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Communication and Journalism

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WHEN VISIONS CONVERGE AND COLLIDE: A FANTASY THEME ANALYSIS OF STAFF PARTICIPATION IN THE PATIENT- AND FAMILY-CENTERED CARE INITIATIVE AT THE UNIVERSITY OF NEW MEXICO HOSPITAL

 $\mathbf{B}\mathbf{Y}$

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THESIS

Admitted in Partial Fulfillment of the Requirements for the Degree of

Masters of Arts Communication

The University of New Mexico Albuquerque, New Mexico

May 2013

ACKNOWLEDGMENTS

I would like to thank Dr. Judith McIntosh White for her tireless commitment to assisting me with this research and for advising me in my graduate program. I would also like to thank Dr. Karen Foss for signing on to be a reader for this project and for coffee meetings. None of this would have been possible if Dr. Donald Shields had not made himself available, across the country, as a close advisor. I am a huge fan of the work that Dr. Shields, Dr. Bormann, and Dr. Cragan have achieved and it has truly been an honor to work with a pioneer of Symbolic Convergence Theory.

I would also like to acknowledge the support, friendship, and mentorship that I have received from Tanya Baker McCue from the Center for Development and Disability at the University of New Mexico. Thank you.

This study would not have been possible without the support and participation from Dr. Duran and Dr. Bluefeather from the University of New Mexico Hospital and I am eternally grateful for your willingness to let me into your world.

To my husband, Paul, my parents George and Toni, and my in-laws Rick and Connie, I would like to acknowledge the many hours that you provided safe and thoughtful care to watching over my daughters, Lily and Lola.

Finally, to my Lily I would like to acknowledge that you have ignited my passion through your brave struggle. To my Lola, you have sweetened my world with your tender heart. I want nothing more than to make you proud.

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ABSTRACT

Using Symbolic Convergence Theory (SCT), this study sought to determine the rhetorical vision of staff at UNM hospital about working with patients and families and comparing it to the ideal rhetorical vision that the Institute for Patient- and Family-Centered Care (PFCC) has for healthcare providers. Participant observation methods were employed over a two-month period for seated physician rounds and interdisciplinary care planning and discharge planning meetings at UNMH in a general pediatric unit and a pediatric rehabilitation unit.

Physicians had their own unique symbolic reality that differed from the vision of interdisciplinary groups. Physicians were most concerned with other physicians as villains. Interdisciplinary teams espoused more negative fantasies of patients, diseases, and families and were less likely to practice PFCC principles when planning care. Interdisciplinary teams may not be conducive to PFCC care without strong leadership.

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CHAPTER ONE: INTRODUCTION

Patient- and family-centered care (PFCC) assures the health and well being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. According to the United States Maternal and Child Health Bureau Division of Services for Children with Special Health Needs, family-centered care is the standard of practice that results in high quality services (http://parentsreachingout.org/pdfs/FCCare.pdf).

Despite extensive rhetoric in the medical community espousing the merits of PFCC and federal legislation supporting PFCC initiatives with funding incentives, there still exists significant resistance from medical personnel to PFCC training and protocol. Patterson and Hovey (2000) assert a key barrier lies in attitudes healthcare professionals harbor that families who have Children or Youth with Special Healthcare Needs (CYSHCN) are "overwhelmed, angry, naïve, and have unreasonable demands" (p. 244).

The University of New Mexico Hospital (UNMH) has attempted to address the need for PFCC training for its staff and medical students. The medical school utilizes the services of two programs: Families as Faculty (FAF) and New Mexico Leadership Education in Neurodevelopmental and Related Disabilities (NM LEND), located at the Center for Development and Disability. The goal of both programs is for medical students to gain insight into how families function and feel about healthcare, which leads to the acquisition of communication skills that deliver greater expressions of respect and dignity, information sharing, participation, and collaboration (www.ipfcc.org/faq.html).

In the FAF program, a member of the medical school faculty, a staff member from a statewide, non-profit parent organization called Parents Reaching Out (PRO), and a person that has a child or youth with special health care needs (CYSHCN) present the ideas of PFCC and share personal experiences about ways providers have been successful in practicing PFCC as well as cases where the needs of the patients and families were not appropriately met. Next, students are assigned, as pairs, to conduct a home visit with a family that has a CYSHCN so the family can, again, narrate how PFCC has been successful or failed in the care of their family. There is only one family visit, and it typically lasts two to four hours. Finally, students reconvene for a guided discussion about what they learned that was specific to the family they visited and to find common themes that might inform their future practice of medicine. The last step in the process is for students to complete a family visit analysis worksheet that asks questions about the family narrative and what the student learned.

The NM LEND program involves a one-hour orientation with a member of the School of Medicine faculty and requires students to complete a total of 20 hours of visits with the families. NM LEND encourages host families to include students in doctor's appointments and to visit the child's school, as well as visits in the home.

The staff participate in PFCC focused seminars that are an hour long introduction to the principles of PFCC that includes best practices used by other hospitals, and a presentation by a family member about the ways that PFCC care has been successfully practiced or breached in the care of their child.

I participated in the FAF program for one year, as the project coordinator responsible for providing the introductory lecture and for facilitating the wrap-up. While I waited in UNMH Tully Hall to present, something caught my attention about the power and impact of provider-provider story telling. Just before every FAF orientation at the UNMH, a veteran, respected pediatrician was scheduled to introduce the students to the professional dynamics of working with the pediatric patient population and to introduce them to strategies for communicating with families. As an ending, each time, she would say, "Now, every once in a while you will get a 'grandma'," making the quotation mark sign with her hands as she said grandma. She would continue to tell a story of a "grandma" who has been all over town with her daughter and grandchild, receiving misdiagnoses, becoming angry and impatient and wanting to do all of the talking. She epitomized the "grandma's" talking using a high-pitched jumble of sounds that illustrated a sort of mocking tone. "So what I do first is physically turn my body *away* from her to give her the first inclination that I want to talk to *Mom* and not her. If she continues then I tell her that we are on the wrong track so I am going to leave the room and come back and we will start again."

There are several troubling parts to the above story if we are to evaluate it with the lens of PFCC. First, this doctor is defining the child's primary caregiver as the mother and insinuates that grandmother is not a valid source of information. The doctor's story does not address factors about the mother's intellectual capacity, the cultural importance of the grandmother as the primary decision maker in some cultures, or who has custody of the child. Second, by using mocking tones and gestures, the doctor has now represented the idea of "grandma" as a caricature to be ignored or dominated.

What is the healthcare staff at UNMH telling each other about pediatric patients and families? How powerful is dramatizing by senior staff when students or new faculty are being indoctrinated into a medical system? Is it possible for stories about patients and families, shared by members of healthcare communities, to negate or nullify any PFCC education or policy that is put in place?

One purpose of this work is to provide an assessment of the degree of adoption of the PFCC idealized healthcare provider vision that is represented in the Institute for PFCC website and literature. Such information may come to aid them in future training and marketing initiatives. Second, I analyze staff interactions at UNMH to understand the vision shared by staff at UNMH about working with pediatric patients and their families. Third, I use the fantasy theme analysis (explained in Chapter 2) to determine the staff vision of other healthcare providers. Finally, I compared the ideal PFCC vision to the visions I found in analysis of staff interaction (talk) to assess any successful convergence or failures to converge between UNMH staff and PFCC principles.

CHAPTER TWO: LITERATURE REVIEW

Introduction

In this chapter, I strive to meet three goals. First, I provide an overview of the history, evolution, and importance of PFCC as a standard in medical systems in the United States. Second, I provide an overview of symbolic convergence theory (SCT) and discuss, specifically, the technique of fantasy theme analysis. I will also provide information about participant observation in general and specific to medical or clinical settings.

PFCC STANDARD OF CARE

Kuo et al. (2012) provided the most current and complete examination of PFCC and its place in U.S. medical systems. They separated patient-centered care (PCC) and family-centered care (FCC) into separate but equal practices in medical settings. The researchers assert that FCC is the correct term for pediatric care because the family is typically intimately involved in the child's care and needs to be considered in the care plan.

Despite 20 years of development, there still remain discrepancies among definitions of FCC. Researchers position the Maternal Child Health Bureau (MCHB), a nation-wide nonprofit called Family Voices, the Institute for PFCC, and the American Association of Pediatrics (AAP) at the forefront of the FCC movement. These groups have been able to reach consensus on some of the principles of FCC, which include "open and objective information sharing between families and providers; mutual respect for family preferences, skills; expertise and sensitivity to cultural and spiritual dimensions; partnership and collaboration in decision making, meeting the needs, strengths, values, and abilities of all; decisions are made including families at the level they choose; and incorporation of families at all levels of care, including encounter, institution, and policy setting" (pp. 298-299).

Kuo et al. (2012) describe distinct differences between the practices of FCC in inpatient and ambulatory settings. Family-centered rounds (FCR) are considered the gold standard of FCC practices for the inpatient setting. FCR involves medical rounds conducted at the patient's bedside and includes family members in the care planning for the day. In the ambulatory (outpatient) setting, the practice of Medical Home is the standard of FCC practice. Medical Home means that a physician, typically the pediatrician or primary care physician serves as a sort of base camp for the patient. If the individual requires care through different specialists and in different clinics, the physician will coordinate all communication to relieve the burden on the patients and their families.

Finally, Kuo et al. (2012) express the need for research about long-term health outcomes for patients that are linked to FCC practices by physicians. They also posit the need for daily practice and exposure to the principles of FCC by healthcare professionals.

Franck and Callery (2004) conducted an extensive critical review of all patientand family-centered care (PFCC) literature to find operational definitions, themes, constructs, and empirical indicators. The authors found inconsistency in definitions of terms and in the practical application of PFCC throughout various systems. The largest deficit cited was that "health professionals' judgments about the credibility of mothers' reports sometimes led them to dismiss important assessments" (p. 268). Franck and Callery were unable to find any evidence that education in PFCC concepts has led to acquisition of skills and suggested that the construct of partnership "should lead to the concept of shared decision-making and sub concept of participation in decisionmaking"(p. 274).

Another study looked at cultural competence, intercultural communication, and family-centered care even more specifically by examining the experience of professionals working with CYSHCN and their parents (Lotze, Bellin, & Oswald, 2010). The professionals studied were participants in the Virginia Leadership Education in Neuro-development and Related Disabilities (VA LEND) program started by administrators for the NM LEND program. Participants completed the program between 1996 and 2006 and had been working in their disciplines for at least one year when they were recruited for the study. The Measure of Processes of Care for Service Providers (MPOC-SP, Woodside et al., 2001) was used. The MPOC-SP contains 27 Likert-type questions that "represented four factors of PFCC: (1) showing interpersonal sensitivity, (2) providing general information, (3) communicating specific information about the child, and (4) treating people respectfully" (p. 103). Researchers also included a qualitative question: "What have been the greatest barriers to family-centered care in your occupation?" (p. 103).

Thirty-three VA LEND graduates replied to a survey with open-ended questions on FCC barriers, identifying five major themes: (1) institutional culture; (2) absence of care coordinator; (3) insufficient training in intercultural/interpersonal communication skills; (4) policy factors; and (5) family factors. Quantitative results showed that "interdisciplinary professionals were providing care consistent with the principles of PFCC in the areas of treating people respectfully, communicating specific information to families, and showing interpersonal sensitivity" (p. 100). The study recognized the small number of respondents and suggested that only those actively engaged in PFCC practices responded. Researchers also recognized that there is no data from practitioners before they attended in-depth PFCC training.

Finally, Johnson, Yoder, and Richardson-Nassif (2006) addressed the effectiveness of family-centered care education on medical students at the University of Vermont College of Medicine. That program was the template for Families as Faculty used by Parents Reaching Out and the University of New Mexico's College of Medicine program since 1997. When medical students completed a visit with their family faculty, they completed and submitted a paper on "what they learned from the family and how that might influence their practice in the future" (p. 225). Three reviewers completed a pilot study of 45 papers collected from July 2001 to June 2002 in order to identify themes. Then, a fourth independent individual reviewed 58 papers completed between July 2002 and June 2003 using the thematic categories provided by the pilot study. An early theme concerned issues families had with physicians; this theme was broken into fourteen sub-themes, all consisting of communication failures. The two most frequent sub-themes of concerns patients had about physicians were failing to listen to and collaborate with families. The authors proposed an evaluation of the application of communication skills as a result of participation in LEND programs.

Symbolic Convergence Theory

Ernest Bormann (1972) introduced the work of Robert Bales's dynamic process of group fantasizing as a starting point to explore dramatized messages (fantasy themes) in larger group contexts. In this work, Bormann established a new theory--later (1982) called symbolic convergence theory (SCT)--and put forth a term he called "rhetorical vision" to describe the group consciousness of a communication community which develops through the process of "fantasy chaining" occurring as a group shares dramatizing messages. Bormann (1985) explains:

My purpose is to illuminate how individuals talk with one another about their here-and-now concerns until they come to share a common consciousness and create a sense of identity and community, how they then use communication to raise the consciousness of inquirers until the latter convert to the new consciousness, and how they use communication to sustain the converted and keep them committed to the established vision. (1985, p. 3)

SCT assumes that humans come together in communication and, through the use of symbols, find commonality and co-create reality. Two of SCT's most ambiguous terms are *fantasizer* and *fantasy theme*. Both require precise explanation for those unfamiliar with the theory. The first response to these terms is the notion of the dreamlike, imaginary, or unreal. The word *fantasy*, however, comes from the Greek word *phantaskisos*, which means to make visible (Bormann, 1972). In SCT, *fantasy theme* describes the sharing of dramatic messages about specific events and people to account for different experiences; fantasizers are players in a rhetorical community that co-create reality by sharing those messages. In healthcare settings, doctors may belong to and construct a rhetorical community through sharing stories (fantasy themes) about patients or families who were angry or who had unreasonable demands. Such dramatizations are either confirmed or challenged by other doctors until the group reaches agreement in a rhetorical vision.

Once a fantasy theme is introduced to a group, a *symbolic cue* -- a joke or shorthand reference to the fantasy theme -- is often produced (Bormann, 1982). The story that the pediatrician told the medical students about the "grandma," using the mocking tone and the hand gesture of quotation marks, produced a symbolic cue. To an average

person or someone who did not receive the same type of dramatizing, this cue might be confusing because more common and widely accepted schemas of "grandma" CAN include love and wisdom. To a member of the medical communication community referenced, however, the cue clearly represented a woman who is angry, belligerent, ridiculous, or should be ignored.

The next step in the process of symbolic convergence is *chaining out*, a series of successive excited or positive responses to a fantasy theme that can catch fire and spread (Shields & Preston, Jr., p. 103). This process builds a rhetorical vision representing a reality experienced simultaneously by the group as a whole. Training in PFCC at the UNMH pediatrics unit is the attempt to build a rhetorical vision that has been experienced simultaneously.

Again, SCT describes the communication process that occurs when a small group comes together to build a group consciousness capable of recruiting outsiders into the same understanding of reality; with the aid of public discourse and media representation, this discourse can produce the shared vision as reality. Public chaining out can occur through the aid of skilled rhetoricians, who employ fantasy theme artistry to create a broad, sweeping rhetorical vision. However, this public symbolic vision does not last forever. It enjoys a bell shaped curve of effectiveness with consciousness building to a peak and then declining after a time. In order to keep an audience engaged, the rhetorical vision must be revised repeatedly to prevent loss of followers of the vision. Once visions are shifted or created, they must be confirmed or modified. Just as visions were impermanent enough to be changed by PFCC training, they can be changed or abandoned through competing rhetorical visions. Bormann (1985) described symbolic convergence theory (SCT) and its qualitative method of fantasy theme analysis as a tool that researchers can use to extract the collective consciousness of a group. One aspect of SCT that is quite relevant to this study is Bormann's description of fantasizing by groups. He described group fantasizing as follows: "as a group's members begin talking about a conflict some of them had in the past or if they envision a future conflict, these comments would be dramatizing messages" (Foss, 2004, p. 111) that depict characters, actions, and themes.

SCT is closely tied to group consciousness-raising. Bormann (1985) indicates that "a pressing rhetorical problem [for] ... aggregates of individuals moving toward a sense of community [that is, participation in a new rhetorical vision] is the creation of a common identity . . . to identify their [new] collective self" (p. 11). Cragan and Wright (1999) detail this four-stage consciousness-raising process and suggest that one of the ways the new identity is created is through *we-they* polarization in group talk. Typically, three types of theys emerge in group conversations: the upward-they, lateral-they, and downward-they. Upward-they talk in my study might be talk about a physician, the management staff of the hospital, or an entire healthcare facility. Lateral-they talk concerns competing individuals or institutions such as physicians talking about another physician, or members of a department talking about another department, or hospitalists talking about insurance companies, or Medicaid. Downward-they talk would be talk about a nurse by a physician, or a family caregiver by a specialist, or the patient by a nurse. In the latter case, Cragan and Wright suggest that a good way to squelch extensive downward-they talk is for someone in the group to use the fantasy type of "don't bite-thehand-that-feeds-you" (pp. 45-46) Such consciousness-raising, Stage 2, talk occurs in backstage behavior.

Although the body of journal articles for SCT is prolific, there are few that look at any aspects of medicine. I am going to provide a brief description of each of the articles and show their relevance to my study.

Barton and O'Leary (1974) used SCT to produce a recruiting campaign that could entice physicians to live and work in rural areas of Minnesota. The researchers used a survey, content analysis of previous recruitment materials, and one-on-one interviews with members of six rural communities who had been unsuccessful in recruiting any physicians in the area. Through fantasy theme analysis, Barton and O'Leary were able to determine that the campaign materials reflected the fantasy themes that the citizens of the six communities held about living in those communities, which were led by an appreciation for "living rural" and for "friendly people."

Although these were visions that were important to the residents of the six communities, these fantasy themes in recruitment material to physicians actually caused a "reverse symbolization" that had negative connotations. The idea of "living rural" was viewed by physicians, not as an advantage to living in these areas but rather as signaling professional isolation from other doctors. The vision of "friendly people" created the impression of an overwhelming workload with a needy population.

The researchers created an intergroup with a representative from each of the six communities and educated them about what their rhetoric was and what implications it had on physician recruitment. Together with a consultant, they were able to reformulate their materials by first hiring a physician who was located in a metropolitan area to recruit and serve as a liaison to interested or newly hired physicians. Second, members of the six communities stopped telling prospective physicians that all of the other physicians had experienced nervous breakdowns or that other physicians had died or committed suicide. Third, a new campaign was created that emphasized freedom for physicians to have more time to spend with family or to attend conferences or produce academic papers.

The new rhetorical vision that was developed was successful in attracting four applicants, and the community immediately hired two physicians after a one-time advertisement in a medical journal. This study illustrated the effectiveness that SCT can have in assessing the needs of two groups and finding ways to bring them together for mutually beneficial relationships. As well, the study demonstrated that a new rhetorical vision can be created and adopted by medical personnel just as anticipated by the creators of PFCC.

Desantis (2002) conducted an ethnographic SCT study about how employees and patrons at a cigar shop rationalize smoking despite years of strong medical evidence indicating that smoking cigars is dangerous and even deadly to one's health. This study demonstrated that a new rhetorical vision like PFCC need not be adopted. DeVargas (2003) explored fantasy themes about how Hispanic women in New Mexico feel about breast exams; she found cultural differences that health professionals need to consider when treating Hispanic women.

Hillyer (2008) discovered an overarching theme, "*It's Still Worth It*," among medical students. Despite the challenges and rigor of medical school, a vision emerged

that medical school still is of great value to this group. This study illustrated that both righteous and pragmatic fantasy themes permeate the vision of would-be physicians.

Stein (1987), investigated group fantasy and its effect on biomedical education and practices. Stein used a case study of a single patient conference for a cocaine addict and performed a fantasy theme analysis. He felt that the decisions physicians made about patient care had more to do with their own personal experiences, as far back as childhood, than the unique symbolic reality and dynamics of the physician group. This study illustrated that vision participation may not influence individual physician practices.

Gangotina-Gonzales (1980) looked at the impact of a rhetorical vision on the views of Mexican-American and Anglo patients and practitioners about traditional and contemporary healers and healthcare providers. The study indicated that those participating in the PFCC rhetorical vision should account for cultural differences.

The SCT work that provided the most relevance to this study was Blassage's (1993) thesis. Blassage conducted a five-step fantasy theme analysis of a non-profit counseling organization called Heartways that provided services to survivors of abuse. The organization was interested in understanding the identity it represented to the staff and consumers. Heartways wanted to grow by attracting new clients and investors but was unsure on how to brand itself.

First, Blassage performed a fantasy theme analysis using interviews and content analysis in order to establish the historical rhetorical vision for the organization--where did it start and what did it become? Next, the researcher conducted phone interviews with staff and patients to establish types of rhetorical visions that represented each of the six possible combinations that may be constructed or derived from Cragan and Shields's (1981) deep structure master analogues that may underlie a given rhetorical vision: pragmatic, righteous, and social as well as social/pragmatic, social/righteous, and pragmatic/righteous. She then compiled themes from several of these competing rhetorical visions into a measure that she administered to consumers of Heartway's services. Through the use of quantitative and qualitative methods for fantasy theme analysis, Blassage was able to illustrate the historical rhetorical vision of the organization as having three distinct sagas and produced the slogan "Healing through Heartways." Her analysis allowed the organization to have a better understanding of the reasons it was started, how time and growth had impacted its vision, and where the organization would need to go in order to ensure that it was providing the proper services to its patrons.

The Blassage thesis is a stellar example of the importance applied communication research can have when used in healthcare and professional settings. Armed with mixed methods and SCT, Blassage was able to extract the rhetorical vision of Heartways. Her work helped to insure Heartways' future success in mental health services by providing its owners with an understanding of the role the therapeutic services play in the lives of its clients; Blassage also made thoughtful recommendations for the future development of socially righteous messages and educated Heartways that pragmatic visions may be ineffective in attracting new clientele.

Finally, a study by Dobris and White-Mills (2006) used SCT to examine the fantasy themes contained within the popular "What to Expect" series about pregnancy, birth, child development, and parenting. The researchers used mixed methods to determine the rhetorical vision of the self-help series. Guided by feminist theory and the

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notions of privilege and power, researchers discovered three paired and contradicting themes: 1) you can do it/you can do this with his help; 2) there is a lot to worry about/don't worry; 3) listen to your doctor/listen to your instincts.

The *you can do it/you can do this with his help* theme occurred most frequently. This empowering and affirming idea of motherhood was accompanied by a significant amount of information warning that mothers might not be fully successful without the help of their male, heterosexual partner.

The next theme, *there is a lot to worry/don't worry* asks parents to relax because stress and worry can lead to overbearing parenthood and health consequences for an expectant mother and her unborn child. At the same time, parents are instructed to keep intense vigilance for warning signs that could signal a litany of serious or fatal diseases.

The final theme, *listen to your doctor/listen to your instinct*, appears in virtually every chapter of the series. Researchers believe the listen to your doctor theme contains "fear appeals that clearly privilege reliance on medical intervention over acting on instincts" (p. 32). Even though there are messages in the chapters about a mother trusting her intuition and possessing some expertise about her child, the listen to your doctor theme occurs four times more frequently. The rhetorical vision of this series decrees that the *sanctioning agent* for motherhood is an "historically male" authority "sanctioned to provide the proper advice and guidance for women who take the role of parent" (p. 34). The study alerted me to the importance of the role of doctor in fostering participation in a rhetorical vision and illustrated that rhetorical visions can contain contradictions and may be less coordinated than expected.

Participant Observation

Communication has a diverse history of employing qualitative and quantitative research methods to observe communication practices. Participant observation is one example of an effective qualitative method. A subset of ethnography, participant observation implies a slightly more active role of the researcher than does basic ethnography. In my case, I have to consider this a participant observation study because I have had previous dealings with some participants and will likely have interactions with participants in the future. They have some knowledge about me, and I have some previous knowledge about some of the participants. If I were to enter completely unknown, like a white man into an isolated Amazon tribe, and provide no information about myself, then I would be conducting the more traditional form of ethnography.

Lindolf and Taylor (1995) provided the most thorough and most frequently referenced text about the history of qualitative communication research methods and the benefits and consequences of using these methods to evaluate communication. They describe ethnography and participant observation as involving "a holistic description of cultural membership" (p. 16).

Lindolf and Taylor (1995) spoke specifically about ethnography of communication (EOC), which "conceptualizes communication as a continuous flow of information, rather than as a segmented exchange of messages" (p. 44). Scholars in anthropology, sociology, and other sciences have employed EOC to gain deeper insight into communication that appears to go beyond simple messages and construct identity, culture, and societal order.

Participant Observation in Health Communication

Lindolf and Taylor (1995) posit that research in the field of health communication has been greatly improved by the introduction of qualitative research methods such as participant observation in order to illuminate patient and provider experiences that could not be described previously with quantitative data. Positioning oneself within a medical organization and observing communication behavior provides a drastically different view than the data gathered by a self-reported questionnaire.

One of the dangers or pitfalls of qualitative research that Lindolf and Taylor (1995) caution against is "what is left out, whose point of view is represented, and how the scenes of social life are depicted become very important matters for assessing" (p. 17) what is key information that the researcher decides to record in field notes. In ethnography, it is imperative for the researcher to understand his or her privilege, agenda, and the choices made in recording data; it is not free from bias.

There is very little in the way of published participant observation in clinical settings. Ellingson (2005) engaged in a two-year participant observation of an interdisciplinary healthcare team at a geriatric oncology outpatient clinic in Florida. Using a combination of feminist theory and dramaturgy from the sociologist, Irving Goffman (1959), Ellingson described the performance of "frontstage" interactions when providers are with patients and the team building and communication that occur "backstage" when the providers interact with one another.

Ellingson (2005) argued that the provider-provider interaction that occurs on healthcare teams holds the key to understanding the culture and communication practices that impact patient care. Following a literature review of current and existing studies on provider-provider communication, Ellingson concluded that this is a significant area missing from the field of health communication. The focus of health communication is largely patient-provider interactions or the evaluation of techniques to reach patient compliance and adherence to treatment. Ellingson heavily references the work of Opie (1997), who suggested "despite the correlations between teams, desired patient outcomes, and employee satisfaction, we know relatively little about day-to-day healthcare communication practices (p. 7, as cited in Ellingson).

Ellingson (2005) hypothesized "backstage team communication (communication among team members without patients present) is interwoven intricately with front stage (healthcare patient-provider communication); the boundaries between these are fluid and permeable, not sharply delineated as they are currently theorized" (p. 8).

O'Halleron, Worrall, and Hickson (2011) performed participant observation on patients engaging in communication with healthcare providers in an Australian acute stroke unit. The unit in Melbourne consisted of 16-20 beds dedicated to newly diagnosed adult stroke patients. Once patients were deemed to be medically stable, a speech language pathologist (SLP) obtained informed consent from the patients because SLPs would have the most expertise in assuring that the patient understood what they were consenting to.

The first dimension of the O'Halloran et al study was the observation of patientprovider interactions such as working with a physical therapist or being consulted by an M.D. Samples were collected by event. Formal categories of activities, such as going to get an MRI, getting out of bed to use the restroom, and physician rounds, were considered unique and separate events. The authors took great care to define and articulate the need for rigor in this qualitative study, based on the suggestions proposed by Lincoln and Guba (1989) and Mertens (2005). They included graphic maps and thick descriptions of the physical space and the events, in addition to the communication that occurred. The most important aspect of the O'Halloran et al study that is pertinent to my study is the lengthy discussion of objectivity of the observer in a participant observation. The authors argued that it was vital for the researcher in participant observation to put their assumptions about the characters, settings, and communication practices in writing before they began their observations and for the researchers to develop measures to control against bias. This included keeping a journal throughout the observation to look for any possible influence that observation may have had on the researcher to create bias. O'Halloran et al were able to illustrate that providers in the unit needed communication training on how to interact with patients who had experienced loss of language due to an acute stroke and that interactions depended largely on the personality of the provider.

Research Questions

Following the parameters set by the research problem and literature review, I have developed and will seek to answer the following general research questions:

- **RQ 1:** What is the idealized rhetorical vision of PFCC for healthcare providers?
- **RQ 2:** What are the rhetorical visions about patients and families being shared by health providers at the University of New Mexico Hospital?
- **RQ 3:** What are the rhetorical visions about healthcare providers being shared by staff at the University of New Mexico Hospital?

RQ 4: How do the rhetorical visions regarding patients and families of staff at University of New Mexico Hospital compare to the idealized rhetorical vision of PFCC?

The next section will describe the methods I used to answer these questions, a

description of the study population, and a discussion about my role in the research

setting.

CHAPTER THREE: METHODS

Introduction

In this chapter, I focus on the methods I used to conduct this study. The methods chosen and employed for this research were inspired largely by Lindolf and Taylor's discussion of (1995) participant observation and by the SCT research program for fantasy theme analysis.

Study Design

This study was a participant observation. For 20 days I was present at all seated rounds in UNMH's General Pediatric Unit (GPU). Seated rounds are meetings between attending physicians, interns, medical students, and residents to determine the care plan for that day for each patient on the unit. I arrived approximately twenty minutes before the rounds began at 9:00 a.m. and sat in the "alley," which is a shared workspace for the unit's physicians. During the pre-rounds time, if a resident or physician was called to consult in the emergency department, I traveled with them and observed their interaction with the physicians from that unit. At the conclusion of the morning seated rounds, the group traveled to the radiology department to review diagnostic testing for each patient. I traveled with the group and observed the radiology meeting. I also observed the discharge planning meetings for the GPU that were attended by attending physicians, nurse supervisors, social workers, and discharge planners. As well, I observed the weekly interdisciplinary meeting that occurred on Tuesdays for the Carrie Tingley Inpatient Rehabilitation Unit at UNMH, which is a care conference of therapists, doctors, nurses, and administrators.

The population being studied for the GPU unit seated rounds were attending

physicians for GPU, pediatric and family medicine residents and interns, and fourth year medical students in their pediatric rotation. I also observed attending physicians, residents, and interns from specialty disciplines when they entered GPU rounds for consultations. The focus of this study was provider discussion about patients and families.

This study utilized a convenience sample. There was no targeted population or recruitment process. I observed any staff member who was present during the observation period. I selected UNMH as the study location because I have experience facilitating the FAF program, I participate in the UNMH PFCC Advisory Council, and my daughter has been a consumer of healthcare at UNMH since 2009. I also worked with UNMH because of their extensive use of PFCC training and policy and their willingness and enthusiasm to participate in this study. Finally, because UNMH is a state funded teaching hospital that is linked to the University of New Mexico, I was able to receive all security clearances necessary for my entry into the pediatric units.

Additionally, I used an SCT-based fantasy theme content analysis of existing public web-based material to produce the idealized PFCC rhetorical vision. The information I used came from the website for the Institute of Patient- and Family-Centered Care. I reviewed the main page, content links to testimonials by participating hospitals, and articles about PFCC.

A Glossary of relevant theory concepts and technical terms can be found in Appendix A. The study's transcribed field notes comprise Appendix B. **Data collection and Analysis**

The data for the fantasy theme analysis of the hospital staff's talk was collected through participant observation and recorded using field notes. I positioned myself in the rounds so that I was out of the way; participants were not able to see my notes. I used pen and paper to record communication exchanges that occurred, including casual conversation outside of the structured rounds, and attempted to record instances of nonverbal communication. No personal or identifiable information about the healthcare professionals involved in the conversations or the patients whom the conversations are about were recorded. I recorded only the biological sex and the age of the patient and the biological sex and rank of doctors (attending, resident, third-year or fourth-year medical student). All healthcare professionals other than doctors were recorded as biological sex and as either administrative staff, nursing staff, or rehabilitation staff (which included physical therapists, occupational therapists, respiratory therapists, and speech language pathologists); because such staff are so limited in numbers, the ability to maintain anonymity would not be possible without grouping them all together. I was the only person who analyzed the data, using the recommendations for analysis articulated in the SCT literature.

I secured approval from UNM's Internal Review Board (IRB) to conduct this study with a waiver for written consent. Per IRB stipulations, I introduced myself by name and program of study, gave a brief explanation about the purpose of the study, and asked if anyone would like me to leave the room. No one objected to my presence, so I was able to remain to observe all rounds.

As indicated previously (page 11), the purpose of this study was not to look at diagnoses or patient care, but specifically concerns the messages that were passed

between healthcare professionals and the resulting fantasy themes and rhetorical vision(s) about working with patients and families that would indicate the participation on non-participation in the PFCC idealized rhetorical vision. Field notes were reviewed to redact any identifiable information. No biological samples were collected for this study and no protected health information (PHI) was recorded.

As described in the literature review, this study's methodology consisted of participant observation because I am currently engaged in an ongoing staff training initiative in the hospital, where I co-teach a one-hour seminar on PFCC. This seminar includes personal information about the illness of my oldest child. It is likely that some staff may have participated in this seminar and, thuswill have information and perhaps opinions about me, which might have biased their behavior or our interactions. I also sit on the hospital's Pediatric PFCC Advisory Board.

To maintain strictest confidentiality and to compensate for any knowledge physicians may have about me, I conducted myself as discretely as possible. I offered as limited information about myself. If asked to give my opinion on the things I had heard and seen, I declined to comment. I did not interject or ask any questions that could be perceived as leading or expressing an opinion. I kept my notes with me at all times and did not talk about what I had observed with anyone outside of my thesis committee. I collected data on a total of 20 "days," which included GPU rounds, discharge planning, Carrie Tingley care coordination meetings, and often a combination of the three types of meetings. All field notes were typed by me into Word format, redacted for identifiable information, and printed. I read through the field notes from start to finish four separate times before making any annotation. I analyzed the field notes by looking for the various themes having to do with *location* or *scene*, *character* or *dramatis personae*, and *action* or *plotline*.

I first performed fantasy theme analysis on the Institute of PFCC in order to gain insight into the ideal PFCC rhetorical vision. By reviewing information presented by IPFCC on its website, I analyzed the content in the same manner that I later used to analyze the field notes. Finally, I compared the themes found in the field notes from my observations of staff interactions and the content analysis of the IPFCC literature to produce recommendations for the organization. I also compared the discovered or actual rhetorical vision to the idealized rhetorical vision of the IPFCC.

CHAPTER FOUR: RESULTS

Findings related to Research Question 1

What is the idealized rhetorical vision of PFCC for healthcare professionals?

Idealized rhetorical vision for PFCC.

Before I begin to analyze staff interactions to ascertain the degree of acceptance or rejection of the idealized PFCC rhetorical vision, it is necessary to construct the idealized rhetorical vision that emerges from my review of the PFCC literature and discourse. The following is a fantasy theme analysis of the Institute for PFCC website (www.ipfcc.org).

The PFCC's idealize rhetorical vision structural elements include: 1) the vision's *genesis sa*ga as depicted in the literature; 2) the *dramatis personae* or characters in the vision; 3) the vision's settings or *scene*; 4) the visions actions or *plotlines*; 5) the presence of any *fantasy type*(s) driving the vision; 6) the vision's deep structure (righteous, social, pragmatic or mixed); and 7) the *sanctioning agent(s)* that leads to the acceptance and promulgation of the rhetorical vision.

Genesis saga. Many health professionals credit the creation and development of PFCC rhetorical vision as stemming from the late Surgeon General C. Edward Koop's call for "family-centered, community-based care for children with special health care needs and their families" (Koop, 1987). For example, Arango (2011) stresses that Koop's was "a message that resonated with families and professionals alike." Arango went on to indicate that across the next 20 years, the American Academy of Pediatrics and the American Academy of Family Physicians were soon on board along with other consumer

organizations like the Institute for Family-Centered Care [now PFCC], as well as other government agencies within the Department of Health and Human Services and the Department of Education. Eventually FCC wound its way as the standard of practice for all children through incorporation into the Title V [Maternal Child and Health] program (Arango, 2011). Thus, funding and its incorporation as the standard-of-good practice provided the sanctioning agent for the patient and family-centered care rhetorical vision (Institute for FCC, 2008).

Patient and family-centered care "is grounded in mutually beneficial partnerships"—the reader should note that "partnership" is the *fantasy type* that serves as the workhorse driving this rhetorical vision—"among health care providers, patients, and families. It redefines the relationships in health care" (http://www.ipfcc.org/faq.html). Furthermore, PFCC "is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions" (http://www.ipfcc.org/faq.html). Thus, the characters for PFCC idealized rhetorical vision are families, patients, and healthcare providers. All characters in the PFCC idealized vision are located in the United States and engage in neurotypical (having no learning or cognitive impairment that would impact communication) conversations conducted in English. Although the plotlines and principles of PFCC make room for application to people with communication barriers such as speech disorders, language differences, or disabilities, these are not specifically addressed within the current PFCC rhetorical vision. Furthermore, PFCC does not delineate the attributes of any specific *dramatis persona* such as grandmother, father, or sister in the family. Rather, the characters named and the plotlines given for PFCC are designated only for patients, families, or providers.

The word *family*, in the PFCC context, and as defined in Appendix A, follows the American Academy of Family Physicians definition

(http://www.aafp.org/online/en/home/policy/policies/f/familydefinitionof.html, 2013), and refers to "two or more persons who are related in any way—biologically, legally, or emotionally" (http://www.ipfcc.org/faq.html). Thus, rather than rely upon a strict legal definition, patients and families are allowed to define what for them is meant by the word, "family" (www.ipfcc.org). In the PFCC idealized vision, family is seen as a character that is uniquely equipped as a whole with little designation given for the people that make up the unit. The family may be of any [socio-economic standing or education level.

Patients, as described in the PFCC rhetorical vision, and in the methods section, consist of anyone receiving medical treatment or consultation by a healthcare provider. However, in the PFCC idealized rhetorical vision, patients are no longer mere "passive recipients of care;" rather, they are "active participants in care and decision-making" (http://www.ipfcc.org/faq.html). However, as indicated in the design section of the methods chapter, for the purpose of this study, the patient is 18 years old or younger. Nonetheless, PFCC is designed for all ages and can include all races, or socio-economic stations. PFCC is the standard of care, as ascribed by the American Pediatrics Association because the pediatric patient is more likely to be dependent on family to make medical decisions and to administer care.

In the PFCC idealized rhetorical vision for this young age group, the character of patient is subordinate to medical providers and is, therefore, in position to be cared for and instructed but not valued as authorities or knowledgeable partners. Here, the

idealized PFCC vision differs from the role it envisions for adult patients as collaborators. In any vision that has heroes and villains, the youthful patient would be the victim that is needing to be saved. With core principles that stress a social deep structure, the rhetorical vision emphasizes partnership, collaboration, and unbiased information sharing. In so doing, PFCC is illustrating that these pillars are not a part of typical patient-provider interactions concerning under-aged youth. The goal of the idealized PFCC rhetorical vision with youths who are patients is to give a strong voice to family as the patient's voice or representative.

Healthcare providers as characters in this idealized vision are any individuals in a healthcare setting who interact with patients and families. This includes support staff such as medical assistants, janitors, or receptionists. However, most often, the healthcare provider is a medical professional such as a doctor or nurse. Healthcare providers are primarily responsible for initiating PFCC communication through thoughtful dialogue. The villains of this vision are providers, healthcare professionals, and medical systems that violate these responsibilities. An example of this violation might be an ER doctor sending a child with acute asthma home with a prescription for "Q4" which would mean that some member of the family would have to administer the asthma treatment to the child every four hours, including during the night. Over even a few days with this situation, the amount of strain on the family could become immense. A doctor who is practicing the ideal vision of PFCC would either keep the child in the hospital to allow the nursing staff to provide the late night treatments so the family can sleep, or would send a home-health nurse to stay with the child overnight and administer the treatment. This PFCC approach would deliver the medical care the child needs while considering

that the family may have to work the next day, or may not be able to provide the care necessary once they become exhausted. The performance of this plotline would provide a reality link to the PFCC ideal vision and the character of dramatis persona *villain* for this provider would be transformed into *hero*.

The heroic idealized dramatis persona of the PFCC plotline are individual providers or systems that go above and beyond the status quo of healthcare interactions and accommodations to: a) listen to the concerns of patients and families; b) invite the patients and families to assist in the process of determining what treatments and services would produce the desired outcome; and c) provide options that would yield the best patient outcome that is commensurate with the needed treatment and is considerate to the skills of the patient and their family. Ideally, these types of actions are provided by the dramatis persona known as the *healthcare team*.

The Institute for PFCC, through their website, literature, international conference, and education programs, produce a vision that contains the principles of respect and dignity, unbiased information sharing, partnership, collaboration, and mutually beneficial relationships. These principles serve as the action words or plotlines for this vision. These are all examples of the underlying social master analogue (deep structure) of the idealized rhetorical vision.

Plotline. The first plotline/action that is integral to PFCC's vision is the *mutually beneficial relationship;* patient and family have knowledge and expertise that the provider needs in order to do his /her job well. In this plotline, providers appreciate that there are aspects of the patient's condition and lifestyle that might not be clear through traditional patient interviews and controlled interactions in medical settings. Those details

may be paramount in constructing the most successful treatment strategy. Building such a relationship with a child's caregivers is essential in a children's hospital. The *fantasy type*, or engine that drives this plotline, is patients and families as *allies* "for [the] health, safety, and well-being of patients" (www.ipfcc.org). As operationalized by various institutions adopting PFCC, the goal is to "encourage families to participate in the care of their children during any and every hour of the day," says Steve Stephenson, M.D., the medical director of Blank Children's Hospital in Bethesda, Maryland (http://www.ipfcc.org/profiles/prof-blank.html). Another means of operationalizing PFCC is by including families in team oriented hospital rounds to increase transparency as is encouraged at the Cincinnati Children's Hospital

(http://www.ipfcc.org/profiles/prof-cinn.html). Other strategies, as suggested by the PFCC program at the Joe DiMaggio Children's Hospital in Hollywood, Florida, range from family oriented needs assessment, orientation, and family mentoring to evaluation by the family (<u>http://www.ipfcc.org/profiles/prof-joe.html</u>). At St. Jude's Children's Research Hospital in Memphis, the program embraces the PFCC vision's four central concepts: communication as information sharing, dignity and respect, involvement of family, and collaboration through partnership (<u>http://www.stjude.org</u>).

In the PFCC idealized rhetorical vision, respect and dignity are expressed when "health care practitioners listen to and honor patient and family perspectives and choices" and "patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care" (<u>www.ipfcc.org</u>).

As to the underlying dynamic, the deep structure, of PFCC, this is highly humane rhetorical vision and thus exhibits a social master analogue deep structure with the plotline of "honoring patients" through the act of listening and incorporating their unique needs into the plan for patient care. The plotline for the PFCC idealized rhetorical vision is to "educate and include family" (www.ipfcc.org). Inclusion is best accomplished through communication such as information-sharing.

The concept of information-sharing, as taken from information systems theory, displays actional (me to you), interactional (me to you and you to me), and transactional (jointly negotiated) dimensions (Cragan & Shields, 1998, p. 49). In the PFCC idealized rhetorical vision, information-sharing occurs when "health care practitioners communicate and elicit and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families provide and receive timely, complete, and accurate information in order to participate effectively in care and decision-making" (www.ipfcc.org). PFCC asks providers to "affirm" patients and families with "useful" information, which is highly pragmatic. The concept of "timely" information-sharing is uniquely pragmatic while "complete" and "accurate" denotes a righteous deep structure communication dynamic undergirding the vision.

The idealized partnership happens when "patients and families are encouraged and supported in participating in care and decision-making at the level they choose" (www.ipfcc.org). Such partnership participation is, again, a major element pointing to the social deep structure of the idealized rhetorical vision and, as well, when observed a reality link to the social dynamic of this vision. A good illustration of the social structure of the vision can be illustrated by the hypothetical instance of the likely provision of an interpreter where there is a language difference or hearing impairment, or at a minimum, in such a case, the provision of a visual aid, or some other thoughtful, adaptive action that would insure patients and their families are able to engage in the fantasy type of *partner*.

Respect is another plotline of the idealized PFCC rhetorical vision. This plotline addresses families that are problematic to providers because they do not wish to participate in care for the child. The respect plotline speaks to the fact that, as in most human relationships, individuals and families may vary in the level of responsibility and engagement they wish to have with providers.

Collaboration is expressed when: "Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education" (www.ipfcc.org). This is a righteous and social analogue with the plotline of inclusion of patients and families at all levels of operation in medical systems.

Sanctioning agent. It is unclear if the *sanctioning agent* motivating acceptance and continuation of the idealized PFCC rhetorical vision is improved healthcare, by itself, or the improved experience of healthcare for patients, families, and providers. Proponents suggest "the practice of patient- and family-centered care has shown evidence-based positive outcomes in terms of quality, safety, and patient/family satisfaction, which support its validity and value." (http://www.ipfcc.org/advance/topics/videos.html) However, this information appears to be an afterthought to the overall social vision represented by the PFCC materials. Perhaps the Institute for PFCC has realized that its social vision was not sufficient to retain the participation of physicians and tacked quality on instead of revising the overall vision to be a mixed social/righteous vision. The result is a contradictory rhetorical vision that can cause difficulty in consciousness-raising for healthcare staff. The rhetorical vision now says PFCC is all about quality but only provides instruction in how to improve service.

Findings related to Research Question 2

What are the rhetorical visions about patients and families being shared by healthcare providers at the University of New Mexico Hospital?

After reviewing the data for this study, it became clear that disparities in participants' symbolic realities meant that two related rhetorical visions were present at the UNMH. The majority of physicians appeared to possess a symbolic understanding that varied from the vision shared by other staff within the hospital. Thus, I will address this research question by first talking about the rhetorical vision of doctors (practicing physicians, residents, interns, higher year medical students), and then the vision of the interdisciplinary teams (nurses, therapists, administrators, etc). I will also provide data showing alignment with the idealized rhetorical vision of PFCC and report data illustrating PFCC successes and shortcomings also broken into the same two categories of physician and interdisciplinary teams.

Rhetorical Vision of Doctors: Characters

The main characters for the physicians about patients and families are: 1) amateur (which can apply to family, HC providers or doctors, and patients); 2) family as villain; 3) scene as villain; 4) mom as villain; 4) grandma as heroine; 5) *wuss*; 4) patient as disease (interesting or boring); and 6) disease as villain.

Amateur. One character surfaced for the physicians at UNMH. I have chosen to call this character the *amateur*. Physicians apply the amateur characterization to patients,

families, and seemingly incompetent doctors and healthcare staff. Amateur reflects a fantasy type dramatis personae stock character whose name changes with the vision. In Old West rhetorical visions, it is the "tenderfoot;" in academe, it is the "neophyte;" with cops and sports it is the "rookie;" in farming, it is the "greenhorn;" in fraternities and sororities it is the "pledge." In the hospital, amateur serves as a derogatory term denoting someone without medical expertise. This is not the same as a villainous character who performs medical malpractice.

Examples of denoting families as amateurs often concerned requests for medical interventions that seemed ignorant or ridiculous to physicians, such as requesting a child go home with a drain in their brain, or exhibiting a fixation on the child's dental cavities when the child is inpatient for a much more serious condition.

Attending:

Mom seems to think he can go home with an internal shunt (laughs).

There was also a joke about a mother's perception of a child's seizures being most noticeable in the way the eyes moved. This was very funny to the physicians, perhaps because rapid involuntary rhythmic eye movement is a fairly common symptom of occipital lobe seizures.

Intern:

We are focused on (laugh) the eye deviation.

For another mother, several physicians had attempted to educate her about her child's serious infection but she was having a hard time understanding and was being perceived by the staff as either being difficult or dense.

Medical Student:

Mom seems to be aware of infection (laughs).

All first time mothers were included in this amateur characterization, resulting in a few conversations about how "they overreact."

Intern:

First time moms overestimate spit up and until we see them spit up we don't really know what happens.

When a parent misreported medical information or seemed to have difficulty

understanding medical information, the physicians seemed frustrated.

Senior Resident:

She said the doctor told her the EEG was fine. Mom may have receptive issues.

Attending:

Okay (rolled eyes and laughed).

Resident:

I don't know what mom means.

Attending:

We just have to get the records.

The institution of parenting also seemed to be the source of some amateur

labeling. When parents didn't feel comfortable traveling across town to fill a prescription, the attending's response was quick and sharp.

Attending:

I totally understand where she is coming from but there are plenty of other pharmacies and she will have to go where the drugs are. Sorry, but... For one child, the patient was being kept inpatient until the physicians could verify that the parents knew how to feed the child properly.

Intern:

Family has complications -- they have other children at home who are sick and the grandmother is sick and apparently had to be taken to the hospital and only one car.

Attending:

I understand, but a child is a 24-hour job and they have to be here -- even if it is just one parent.

Patients as amateurs often tended to be teenagers who had injured themselves either intentionally or unintentionally, such as the child that swallowed glass during a fight with his mother or the girl who overdosed on cold medicine. One young woman ingested an entire box of cold medicine. One physician in the group indicated it was unfortunate that she had done such a thing and another indicated the seriousness of the situation by noting that it could have been a suicide. Another physician seemed to make light of the situation and the last made a joke of the situation and others like it.

Senior Resident:

Poor thing!

Attending:

Not a suicide attempt and just wanted to get high. Senior Resident:

Could have been a suicide!

Senior Resident:

Because of these kids we have to sign for Sudafed!

Although the amateur characterization painted many patients, family members, and healthcare providers as villains, it must be emphasized that they were villains because they served as impediments to good, quality health care demonstrating participation in a rhetorical vision emphasizing a righteous, or correct, way of providing good, quality care.

Family as villain. Family as villain occurred in physician meetings; for the doctors, this villain more often applied when there was a lack of appropriate action by the family for the benefit of the patient. For example one doctor described a mother as a "horrible mom" who "just made bad choices" and didn't provide optimal "social support" for her young boy with cystic fibrosis. Lack of social support served as the catch-phrase to depict the home scene as villain to the PFCC rhetorical vision.

Scene as villain

During one of the morning seated rounds, the female senior resident took the time to talk with interns about the likelihood that they would be working closely with the Children, Youth, and Family Department (CYFD) on abuse cases and acknowledged the difficulty that can exist with sending children home.

Senior Resident:

You made them better, you healed them with your knowledge, and you know they are going back to the people who hurt them in the first place.

In another patient's report, the team began to talk about the possibility of home neglect and abuse by the family, based on information they had received from the nursing staff.

Attending:

Nursing staff noted family left with crib rails down and fork and knife and bubbles in crib. Might be bad parenting.

Mom as villain. A young boy who was a regular patient on the unit became the subject of conversation in the office area one day. He was not a candidate for a lung transplant because his social issues were too great.

Attending:

...and then there was the mother. Once again! She said that she didn't want to make the decision [to put a trach in him] until the tube was right in front of his face. No decision is a decision and it is not responsible because it is going to mean a horrible, painful death for him!

Attending:

(whispering to me) Nice kid, horrible mom.

Grandma as heroine. Where there was a case of a grandmother caring for a grandchild, she was often viewed as a heroine. There were two children – one male, one female -- with such chronic illnesses that each spent significant time on the unit. Both had traveled from rural communities in New Mexico and were several hours away from home. One was from a Native American community and the other from an Hispanic community. I was unable, through the conversations I observed, to ascertain the specific heroic actions of the grandmothers in these situations but it was apparent that the physicians, on the whole, were impressed with the care provided by the grandmothers. In fact, when one specialist made a disparaging comment that could have been perceived as

being an attack on the grandmother, the other physicians stood their ground in defense of her.

Specialist:

This child is just awful, looking at the hips. Is she DNR?

Intern:

No, she is Native.

Intern:

Grandma takes meticulous care of her.

In the case where a child was in the legal guardianship of his or her parents, the physicians often took care to mention the grandmother in their rounds.

Medical Student:

Grandma was bedside nurse. Grandma is there with the child most of the time.

There were also indications that the grandmothers were included in reporting medical information and were often viewed as an important support to the mother of the patient.

Medical Student:

I'm going to test the waters with Mom and Grandma

Attending:

Grandma indicated that the child has a cousin with seizures.

The above demonstrates that many of the doctors participated in a rhetorical vision that mirrored the PFCC's expansionist definition of family.

Wuss. Early in my observations, I witnessed three conversations about young boys being characterized as a *wuss*. These conversations were initiated and sustained by the same female attending physician as she talked with other pediatricians. The children she referenced were boys under the age of 13 who had had a difficult time coping with painful procedures.

Attending:

My patient is a huge wuss.

Attending:

No, that patient wasn't a wuss. He was just over narcotized.

Attending:

He's being a 'jito'.

Intern:

No a chione--a cry baby.

Other attending physicians initiated character descriptions that approached "wuss" and included young girls, though they were usually referred to as being dramatic or whining.

Attending:

She is developmentally delayed so I can't get a good idea of what hurts. Kind of just whining today.

Attending:

She is kind of difficult.

One medical student engaged in a quiet side conversation with me in the "alley." It appeared that he sensed the inclination for some of the staff to make fun of or downplay the pain that the pediatric patients were having. He said that it was really hard to get "people" to understand how painful bone infections were. I asked if it was hard to get the patients to understand or their family, and he whispered: "hard to get the staff to understand." I asked if he felt they were under medicating the patient in question, and he said, "Yes, we have the drugs to treat the infection and the drugs to help with the pain and we should be using them."

Patient characterized by disease. Patients were most often described by their disease and were frequently broken into either an interesting or boring diagnosis. Interesting diseases were rare or complicated and required deep thought, peer consultation, or intense planning on the part of the physicians. One patient had an unidentified object in his guts that required several images until doctors were able to determine what was causing a gastric blockage. It was determined that some fecal matter had collected in a part of his intestines. This gave way to a dramatized characterization of the patient as "an oyster-making boy" by an attending physician, whose elaborations of the fantasy theme were accompanied by boisterous laughter indicating the sharing of the chaining character fantasy theme.

Attending:

Our little oyster with the poop pearl.

Resident:

I dare you to wear it around your neck. Attending:

No way!

Another specialist who had no personal contact with the patients but only viewed diagnostic results had a tendency to characterize the MRI and CT scans of her patients' diseases as boring or uninteresting while at the same time describing what she was seeing as villainous.

Specialist:

This [scan of the torso] *pattern is boring. I assume the head CT* [CT of her head] *is boring too.*

Specialist:

Horrible lungs. Her [disease] is awful.

Attending:

This is one of three kids who have [the disease] in the family.

Specialist:

Oh, isn't that special. Geez Louise!

Specialist:

[In response to someone mentioning a kid eating glass] *I don't get that one.*

Specialist:

This MRI is awful. It is enhancing hideously. This is icky.

In other cases, patients who exhibited chronic illnesses regularly became

characterized by their diseases, as opposed to their name.

Attending:

These CF kids get colonized with bacteria.

Medical student:

Do CF kids have their own growth chart?

In the case of patients who exhibited diseases that were common or required very little thought to diagnose or treat or were otherwise uninteresting to talk about, their diseases were labeled boring. Nevertheless, attempts were usually made to discuss the patient's medical problems in earnest.

Specialist:

This pattern is boring. I assume the head CT is boring too. Attending:

This is probably a straightforward case but we can pretend he is interesting.

Disease as villain. Finally, the true villain of the pediatric inpatient unit was disease. The physicians in this study acknowledged certain powerlessness over mortality. There was recognition by health providers participating in this vision that no matter what the doctors do, a disease process can be more powerful than their best efforts. Barton and O'Leary (1974) concluded that a key component to a physician's rhetorical vision is "power over life" (p. 150). However, through experience, there are some illnesses that are more cunning and have resulted in physician failure.

Attending:

We treat asthma so often we can get cavalier but remember that asthma kills healthy people all the time. It is very serious, and I take my time and I am aggressive with treating it.

Intern:

Asthma scares me. We had a kid who was a 14-year-old athlete who had shortness of breath and went to PCP, was cleared, went home and sat on the couch to rest and when mom came to check on him he was blue. He went to ICU, ECMO, and he died. 14-year-old baseball player. Asthma scares me too.

Rhetorical vision of doctors: Plotlines

The actions that drive this symbolic reality, the plotlines of the vision, were heavily focused on the professional responsibilities of being a physician. Several conversations emerged that showed a self-consciousness of group members to monitor their actions in an attempt to avoid being the "other doctor," that is, the amateur. This leads to the proposition that the profession of physician is the *sanctioning agent* for the doctors.

This proposition was routinely supported by use of the plotline *fantasy type*, "Dr. knows best." The greatest authority or judge is those with an M.D./O.D. Thus, the physicians themselves are the *sanctioning agent*, ultimate legitimizer for their mixed righteous and social rhetorical vision, and for patients, their families, and for their colleagues. Although God was mentioned in conversation, there was never any indication that God served as a sort of guide or judge of their actions.

The "Dr. knows best" fantasy type drove the PFCC rhetorical vision as it was implemented at UNMH. Evidence of this was apparent in the "family must be convinced Dr. knows best" plotline that appeared several times. The education and mastery of medicine that physicians have acquired empowers them to heal the sick and to save the dying. Portions of some of the meetings were spent discussing instances where a family member did not agree with a diet or a medication that was being prescribed. The physicians had a clear idea of what they wanted to do for the patient but that idea did not always appear desirable to the families, either because the families' perceived it had great risks to the overall health of the child or because the parents felt they had tried something similar before that did not work. When families or patients refused to participate in the care plan prescribed by the physician, they would be labeled as *non-compliant*.

However, in this group of physicians, there appeared to be caution when it came to labeling a patient or family as non-compliant. The physicians encountered in this study, instead, and in line with elements of the ideal PFCC rhetorical vision, expanded the amount of time and care they gave by trying to listen to the concerns of the family and trying to find ways to convince them that the care plan being suggested was best for the child. In one case, a meeting with CYFD was called because the physicians did decide to label the parents as non-compliant thereby preventing release of the child until they had assurance the prescribed diet would be followed by the family.

Intern:

What is keeping child from discharge is diet, as you all know.

For another child, a neurology specialist had ordered a carb-restricted diet for the child. However, the parents indicated to the pediatric hospitalists they were not willing to do the diet because it had been stressful and had failed to produce any real results when they had tried it before. The physicians stressed the need to work more closely in educating the parents, another key value in the ideal PFCC rhetorical vision.

Intern:

Family also did not want to do the carb restriction that Neuro[logy] was recommending because they felt that the child lost weight. Need to check with family and do education because I feel like they are confusing ketogenic diet with low carb diet.

Families and patients are regularly protected by physicians from interdisciplinary team members who don't respect their unique needs, again illustrating physician commitment to PFCC. An example of this involved a teenage mother who had been labeled in the patient's chart as possibly having "social issues" that impeded her ability to care for her child.

Intern:

Night nurse had concern over social issues that mom is young and seems immature. I told her [nurse] Aunt and Grandma are there all the time.

Attending:

Mom has been completely appropriate! I have seen her do every feed. Yes, she is young but being young is not an issue.

Rhetorical vision of doctors: Fantasy type

In addition to the "Dr. knows best" fantasy type described above in discussing plotlines, a key fantasy type in the idealized PFCC rhetorical vision is *teamwork*. Not surprisingly, teamwork serves as a central fantasy type driving behavior for doctors. Physicians work closely with one another, with specialists, and other healthcare providers. Teamwork serves as a means for physicians to educate one another about different areas of experience and medical education. Each physician was responsible for participating with the team in meaningful ways.

Rhetorical vision of doctors: Master analogue and sanctioning agent

The Master Analogue for the physicians appeared to be largely righteous (Dr. knows best about medical care) while at the same time incorporating major elements of the PFCC idealized rhetorical vision (educating parents and other family care givers, using an expanded definition of family, etc). Clearly the physicians were concerned with doing what was deemed best for the patient and doing it correctly. This is seen in the earlier discussion of "amateurs." A physician's "power over life" with the skills acquired via their work experience and medical education make them rise to a God-like position in the lives of patients.

The sanctioning agent for physicians is a professional oath to "First do no harm," as well as provide quality care as prescribed by the American Medical Association. Again, as seen in the "amateur" characterization, each physician takes his/her professional role very seriously and views this responsibility to be greater than all others.

There is indication that the quality of healthcare or the way families feel about healthcare which comprise the PFCC vision has made its way into the physician vision. The physicians regularly exhibited compassion and respect for families as they sought to design care plans that include the needs of patients and their families.

The doctors definitely exhibited participation in a rhetorical vision that mixed the righteous elements of Dr. knows best, disease as villain, and amateurs as villain with the more social humane elements of accepting the extended definition of family, listening to family concerns, adapting care plans to the family situation, and providing the best quality care.

Rhetorical vision of interdisciplinary teams: Characters

The main characters for interdisciplinary teams (social work, nurse, etc.) were family as villain, insurance as villain, know-it-all mother, and patient as villain.

Family as villain. The vast majority of backstage interdisciplinary storytelling about patients and families involved the vilification of families. That is not to say that team members did not regard some families as neutral or ideal, but they did not talk about these types of families during interdisciplinary planning meetings. From tales of mothers who treated hospital staff like employees at a hotel, asking for a "wake-up call," to an hour long rehashing of all of the ridiculous antics of a mother whose child had been inpatient for several months, the stories about families shared in interdisciplinary groups were less than positive portraits.

In contrast to the explanation given by the intern about the angry father who had blown up at one of the physicians because he had received misinformation from two consecutive medical professionals, the conversation about him in the interdisciplinary meetings sought to scold him rather than understand his behavior.

Nurse:

Hey! We diagnosed his kid! Don't know what he is so mad about! You could tell his son was mortified by it. And the mom [Aunt] just sat there blank while he was yelling and didn't say a word.

Administrator:

Poor kid.

The inpatient unit that saw smaller numbers of families for longer periods of time spent a significant amount of time dissecting the character and social composition of families. One of these care meetings lasted for 90 minutes and concerned the planning of care for two patients. The first child's mother had a very positive outlook for his rehabilitation and the resources she will have to take him home.

Healthcare Provider:

Mom is very not a glass ¹/₂ full--glass is all the way full with her son. Administrator:

Not going to be better in 12 months.

Social Work:

Mom thinks she is going to get lots of resources in home. That is not accurate.

Administrator:

Mom needs a talk about real life and how real money works.

A second child's mother was regarded as mentally ill, drug addicted, and very inappropriately behaved. The bulk of care planning was actually a discussion about the odd behaviors she showed when she was on the unit and how the staff felt about her presence.

Healthcare Provider:

Mom has no idea how to handle him. I really believe he is in danger if he goes home with his mom. Mom is convinced he is going to school for engineering and math. It is like she didn't hear anything when we explained brain injury to her. Pretty clueless.

Therapist:

I think people must yell at him all the time because he doesn't even respond.

Healthcare Provider:

Mom has been belligerent when told to get out of the child's bed. She has been reported as tweaking and twitching by one of the nurses and says she is using meth. Mom was so inappropriate in a team meeting last week. Nurse told her "Where did you come from? We had no problems until you got here."

Administrator:

They [grandparents of the patient] *need to give her a lesson in tough love.* Therapist:

Mom just uses therapy as babysitter. She doesn't understand what it is for.

Insurance as villain. It is not surprising that the people responsible for developing care plans for medically complicated patients and for ensuring all services and supplies are provided for patients being discharged would have strong feelings about insurance. Insurance is the sanctioning agent for these groups because the flow of money determines eligibility for services for the patient and family and can override even the righteous vision of the physician. One example involved a family that had to travel from rural New Mexico because the child had been injured and would have to pay to stay in a hotel because of the type of insurance that they had through their employer.

Administrator:

Those who have jobs can't get the kind of care you get on Medicaid.

There was also a lengthy conversation about how different insurance companies pay different rates for inpatient stay.

Administrator:

One company pays a flat rate of \$900 per day for an ICU stay, which is likely to actually cost something like \$4,000-\$10,000 per day.

When it was considered that a child with a fairly rare illness might benefit from traveling to another hospital on the East Coast with more experience treating the condition, the team decided not to try to arrange the transfer because the child had Medicaid.

Healthcare Provider:

Problem is Medicaid. Since we can treat him here, they will not send him.

Not surprisingly, one interdisciplinary care team even joked about a child who was run over by a car as being deemed well enough by the insurance company to have outpatient therapy. This situation was very funny to the group because they had experienced cases for which the child's insurance would refuse to pay for any more therapy services because the insurance deemed the child "well enough." There was also scheming by providers to admit a patient on a Friday and then take their time to evaluate him to buy him an extra week of inpatient care. Another plan was to place a patient in another level of care for a week or two to get him more time as an inpatient.

Know-it-all-mother. The interdisciplinary team produced a character not present in the physician-only meeting, describing some mothers as know-it-alls. In stark contrast to the amateur mother who knew so little about her child's condition that it was laughable or pitiable, the know-it-all mother emerged. She challenged the care team with knowledge about her child's condition unknown to anyone else. For the interdisciplinary team, there exists a continuum for how much a mother can be involved in care. If there is not enough involvement, she is selfish and uncaring, but she can exceed an appropriate amount of participation to move into a realm of being a problem that threatens the work of the care team.

Therapist:

I think we are doing a great job. She is more interested than most moms, which is great, but if we miscommunicate with her she could get mad. She has the possibility of team splitting so we need to be careful with her. Healthcare Provider:

One nurse got mad because she was requesting one thing after the other. Administrator:

I asked if mom needs a team conference and she said no and that she felt like she had good communication with everyone, but if she is saying that she thinks he can walk out of here...

Patient as villain. The interdisciplinary team also produced another character that failed to emerge in the physician meetings, except for its vague likeness to *wuss*. The patient as villain emerged in the interdisciplinary care meetings on the Carrie Tingley inpatient rehabilitation unit. Therapists talked about children, male and female, as being difficult, defiant, disrespectful, and even physically violent. The behavior of the patient served as motivation for some practitioners to refuse further treatment of the patient until the child's behavior improved.

These conversations about patient as villain tended to loop back to family as villain, with the assumption that if the family had been better parents, the child would be more cooperative. Or, if the family were more involved in the rehabilitation, then the

child would behave better. One therapist in particular seemed to view most of the patients as problematic or villainous.

Therapist:

He's tough. He is a safety concern, and he is not really benefiting from therapy.

Therapist:

He complains and whines when he doesn't want to do it. Five months of this! I'm not gonna get a lot out of him. He has a wheelchair, and he can stay in it. He doesn't like me.

Another patient, a five year old whose mother was a frequent topic of lengthy

conversation in the care planning meetings, also was characterized as a tyrant.

Healthcare Provider:

He is kind of a tyrant. I can't stand his screaming!

Therapist:

I tell him "If you are not going to do that, then you are not going home." He has no socialization -- like a wolf cub.

Therapist:

That child needs rules!

Rhetorical vision of interdisciplinary teams: Plotlines

The first plotline for interdisciplinary teams had the members doing their best to prepare the families for life outside of the hospital. This contributed to another plotline which held that most families are so socially complicated by poverty, lack of intelligence, rural living, undocumented status, or divorce, that no matter what the team did, the outcomes would not be ideal. For interdisciplinary teams, the weight of the social needs and deficits of patients and families seemed at times to overwhelm team members.

Many members of interdisciplinary teams indicated that patients and families show little respect for the hospital staff. This became apparent with oft-told stories about family members or patients that treated the nursing staff like maids in a hotel, didn't cooperate with therapy sessions, or yelled at physicians. Patients' and families' not understanding the boundaries to participation expected of them by staff is perceived as an unwillingness by uncaring people to do what is best for the recovery of the patient. It is seen as a personal attack on the individual staff, as well as an illustration of bad upbringing.

Rhetorical vision of interdisciplinary teams: Fantasy type

The fantasy type for interdisciplinary teams is *group work*. This differs from the teamwork that is the fantasy type for the physician groups, because it does not produce the same level of responsibility or identity. Each therapist and administrator has a different job that is not well understood by the other group members. When they come together to share care plans, they have no way to relate their work to that of others, so they seek to make sense through the social aspects of working with the patients and families. They are otherwise working independently from one another.

Rhetorical vision of interdisciplinary teams: Master analogue and sanctioning agent

The master analogue for interdisciplinary teams appeared to be social, because the bulk of their conversation had to do with the humane aspects of patient's treatment and concern for families and their feelings about caring for the patients. These were *not* righteous conversations, because they did not convey the sense that they were being at all

successful or that they had the right answer. The interdisciplinary team members looked to the physician to guide their work, and they made sense of their experience providing care by the quality of the social interactions they had with one another or with patients and families.

The sanctioning agents for these groups appeared to be insurance companies and physicians. The physicians provided the care direction and prescribed what was best for patient outcome, and the insurance company provided compensation for the services. If both the physician and the patient's insurance company did not agree on a care plan, then it did not happen.

Findings related to Research Question 3

What are the rhetorical visions about healthcare providers being shared by staff at the University of New Mexico Hospital?

Rhetorical vision of staff: Characters

"Other doctors." The most frequent dramatis persona to emerge from the doctors was the notion of the "other doctors" as a villain or an incompetent provider. "Other doctors" were likely to belong to a different specialty such as orthopedic surgery or neurology or maybe other pediatric hospitalists at another medical facility. The topic of "other doctors" tended to evolve out of the presentation of new patient history. In one case, a child faced the prospect of having a limb amputated because a previous physician had misdiagnosed or undertreated an infection in the bone.

Attending:

...and now he [other doctor] left the state and she [patient] was passed around and now will likely lose her arm...really, really sad and they are

so nice, so it is really sad.

Another example of "other doctors" occurred when a radiologist reported that a child appeared to only have one kidney in the images from a diagnostic ultrasound. The idea that a trained and seasoned radiologist could misread something as significant as a child missing a kidney seemed both horrifying and comical to the pediatric hospitalists. The result was a symbolic cue about the patient that looked like a joke about his physical ailment but was actually more indicative of the physicians' disapproval of the diagnostic abilities of the radiologist .

Intern:

I think she [patient] is regenerating them and selling them on the black market. The "case of the missing kidney" as it became called even spread into another department in the hospital.

"Other doctors" were the possible reason that a child came into this team's care with old orthopedic pins in his arm, causing an infection.

Resident:

Hospital records show that no arrangements were made for follow-up after discharge.

Another example of "other doctors" occurred when there was a disagreement between the pediatric hospitalists and members of another speciality. The specialists were refusing to discharge an 18-year-old woman with a chronic condition because she had been noncompliant in her care, resulting in her present admission. It was the opinion of the hospitalists that the specialists had misdiagnosed the woman's condition and overridden their recommendations to allow her to complete her treatment in the comfort of her own home.

A 23-month-old female patient was admitted to the GPU and, as the female resident read the long list of medications that the emergency department administered the child for seizures, the room of doctors erupted into hysterical laughter.

Attending:

That'd make anyone feel not so good.

Resident:

Except for tachycardia [caused by all the medication] (laughter) she is all good.

One conversation, involving the pediatric hospitalist team consulting in another department, condemned an entire medical system as being deathly incompetent. One of the private medical systems in Albuquerque is called Lovelace. It has gained a reputation that patients arrive at UNMH as "Love lost," which implies that the entire system and all of its physicians are woefully incompetent. The same thing happened when a group of doctors were talking about Christus St. Vincent Hospital in Santa Fe, New Mexico; some of the residents referred to it as "St. Victims."

"Other doctors" was not always confined to doctors. Within this theme there were also conversations about "other staff," such as a nurse that would give all medications made available for a patient, whether the patient needed a particular medication or not, or a social worker that failed to meet with family, forcing the team to keep a child inpatient longer than medically necessary.

Attending:

Be careful about writing meds because even if they are written specifically just to give if the patient needs them or the parents ask for them, because it gives some nurses the freedom to give them whenever without consulting us.

Senior Resident:

Sometimes the nurses walk around with a napkin or piece of paper and record all of the ins and outs and then enter them all at one time at the end of their shift. So, if you are looking and it's like "this patient hasn't peed in 7 hours!" then you call the nurse and check. Sometimes they haven't peed in 7 hours but...

Interestingly, one of the stories shared about a father as villain spawned from an "other doctor" encounter that the parent had with a specialist and then a nurse. A father was labeled as "inappropriate" and "abusive" by the GPU staff after having an explosive exchange with one of the interns. It was later discovered that his anger was the result of a specialist communicating one care plan, and then the nurse on duty coming into the room to tell him about another care plan "which was wrong." He became mistrustful and frustrated and exploded upon the next person entering the room. The intern he had verbally assaulted became his biggest defender when the story of his outburst was dramatized through the rest of the staff.

The only conversation about health professionals that occurred in the interdisciplinary team came from the mouths of physicians. In the rehabilitation care planning meeting a physician was angry that a specialty wasn't coming to see their patients and was sending interns instead.

Cragan, Kasch and Wright (2009) described a similar occurrence in stage three CR for emergency healthcare workers (p. 55). As the consciousness of members of the groups rise, it can go too high and they become elitist and hard to manage. They can actually cause morale problems in interdisciplinary team settings because they perceive themselves as having more intense or important jobs.

Findings related to Research Question 4

How do the rhetorical visions regarding patients and families of staff at the University of New Mexico Hospital compare to the idealized rhetorical vision of PFCC?

Physician convergence with PFCC vision.

Although some of the backstage visions of patients and families I have discussed in the character section of this work vilified patients and families, the actions of the physicians were often perceived as admirable and consistent with the hero of the PFCC ideal vision.

Educating the family was a significant concern for the physicians and their accepted definition of family met the PFCC criterion. In one instance, the child received the bulk of her care from an aunt while the mother worked. The physicians displayed little more than a raised eyebrow or two but proceeded to make arrangements to ensure that the aunt received the appropriate care education.

Another successful area of convergence with PFCC included making sure medications were available before sending children home. In one case, the attending instructed the intern to find out which pharmacy the family preferred to use and to call to find out what doses of the medications they offered. This was to ensure that providers did not prescribe a dose that would require the family to have to cut pills apart. In line with PFCC guidelines, this action takes into consideration the needs of the family and reduces stress by preparing them fully to care for their child.

Additionally, considering family needs in care plan was noticeably present. This included looking for the strengths of the family instead of focusing only on deficits, embodying the pillar of respect that is a component of the ideal PFCC vision.

Defending parents against character assassination from interdisciplinary team members was another area of success unique to the physicians in this study population. When a patient's or family's behavior came into question, it was always a physician who attempted to rationalize or justify why the behavior was understandable.

The physicians in this study group worked tirelessly to organizing support staff and interdisciplinary team members to provide support and care for families. From the beginning of the day until the end, physicians were making phone calls, emailing, and going from office to office to ensure that each patient was receiving consultations, procedures and education necessary for successful recovery. These physicians made personal calls to pharmacies to ensure that the correct medicine was in stock and worked insurance.

Partnership happened between families and physicians on this unit. A mother was feeling discouraged about her daughter's prognosis and the treatments that she had been receiving because they were not working. The attending acknowledged that the mother's irritation was valid and appropriate and asked the intern in charge of the case to ask the mother if she would like to take over administering one of the child's medications so she felt she had more control over the child's breathing. In some cases, information sharing occurred through patient education, but mostly it occurred through physicians that were proficient in Spanish or through the use of interpreters. Attending physicians strongly and consistently encouraged interns to utilize the hospital's interpreter staff lest it be downsized for lack of use. However, they did caution the interns that sometimes the interpreters seemed to not translate as closely as would be ideal. Bilingual physicians were seen as possessing the greatest advantage in working with Spanish-speaking families, because they had both medical knowledge and a strong grasp of the language. There also are interpreters available for other languages in addition to Spanish.

It is very interesting that the original story of the "bad grandmother" that drove me to participate in this line of research did not appear in the population I studied. In fact, the antithesis occurred where staff held grandmothers to a level of esteem and respect. It is possible that the difference had to do with a difference in an inpatient and outpatient setting. It is also possible that "bad grandmother" could exist even in the inpatient setting but was not present during my observation.

Finally, attending physicians seemed genuinely to care about the wellbeing and recovery of patients and were inclined to consider the needs of the family in the care plan. One mother wanted to leave the hospital so badly that a few of the residents were disturbed by her insistence to leave with the child despite the patient's dire condition. The attending questioned the residents about the race and ethnicity of the mother and discovered that she was Native American. The attending then informed the residents about the healing ceremonies the tribe performed when a child is sick and encouraged the residents to consider that as the possibilities of the mothers desire to leave instead of

thinking she was up to no good. Modeling of the principles of ideal PFCC is the most effective mode of training and it was clear that the residents were going to think differently about this mother after that discussion.

Physician PFCC failure.

Some readers may see significant failure on the part of physicians to converge with the ideal PFCC rhetorical vision and its major plotline of sensitivity and need for respect. Those readers who see failure would seem to do so due to their misinterpretation of the physicians identifying the patient under discussion in backstage talk in the seated rounds by his or her disease and then vilifying the disease. At other times, some readers may interpret health providers' use of words like *wuss* or *crybaby* or *tyrant* in backstage talk as disrespectful. However, such backstage talk neither demonstrates nor indicates a lack of adherence to the idealized PFCC rhetorical vision. Similarly, such talk would only be disrespectful if it was included in frontstage dealings with patients and their families. As indicated in the discussion of consciousness-raising to bring about participation in a new rhetorical vision, the aforementioned backstage talk should be considered as a normal and necessary consequence of CR, rather than as internally motivated by some inner shortcoming or prejudice or intent to show disrespect (Cragan, Kasch, & Wright. 2008).

Physicians continue a traditional, patriarchal and righteous role in the care of the patient. The characters of family and patient as amateur, and family as villain, and patient as disease indicate an attitude of superiority to those being served. The righteous vision leaves little room for the input and opinions of any people outside of the profession of

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M.D. However, as we have seen, the righteous physician vision meshes well with the idealized PFCC rhetorical vision via the oft-used fantasy type of "Dr. knows best."

Interdisciplinary team convergence with ideal PFCC.

Some of the therapists led the charge to involve family in care and practiced unbiased information sharing. Within the team meetings, there were individual conversations about success that therapists had with involving patients and families in care activities. One group acknowledged that a therapist was having great success with a child with whom the other therapists were being unsuccessful. There was a brief acknowledgment of the success of the individual therapist by one of the administrators in the group.

As can be surmised from their discussions in seated rounds, the therapists, for the most part, appeared to develop and follow therapy plans that considered the needs of the patient based on their understanding of the patient's physical condition and home environment. There were also discussions about how much therapy a patient could withstand at one time or in one day, and care was given not to push any child beyond a reasonably cautious therapeutic level of activity.

On several occasions the team members attempted to acknowledge patients' cultures by stating that a particular patient was of a specific cultural or ethnic background. Although this was typically a very brief and surface discussion, it indicated a team's ability to take the needs of a specific religion or culture into consideration when a care plan was at odds with the beliefs of the patient and family.

One physician, again operating from the "Dr. knows best" fantasy type, through thoughtful instruction, altered the group's consciousness-raising *we-they* talk in a care

planning meeting in which they had been sharing villain stories so negative they approached character assassination of patients and families. When one therapist continued talking about a patient who couldn't be rehabilitated because he was too poorly behaved, until the physician intervened and suggested that the child was not complying because he was in so much pain. Once it was clear that the child had a legitimate reason to be non-compliant, the therapist began to talk more sympathetically about the patient and became hopeful about the child's ability to be rehabilitated once his other painful condition had resolved. This occurrence would seem to indicate that as Blassage discovered, there is room for a righteous/social rhetorical vision fostering PFCC in which righteous physicians may more easily participate.

Another healthcare provider in the group started talking about hearing from a different hospital that the mother of an incoming patient was difficult.

Physician:

We don't know what the mother is gonna be like. We are not here to figure her out but to get her kid better.

Here, the physician altered the entire conduct of the group into care planning that approached the ideal PFCC vision. She instructed the group about ways to integrate the *know-it-all mother* into the care plan by giving her exercises that she could do with the child. This physician also encouraged the other team members <u>not</u> to analyze the personal attributes of the parents, but rather to seek ways to involve the families in meaningful activities to allow them to feel more in control of scary and stressful times they are experiencing with their child.

Interdisciplinary team PFCC failure.

The majority of these meetings were focused on deficits instead of strengths of family and patient. There was little to no mention of things that were going well for the patient. The story sharing was almost always negative, except in cases when the child was good at drawing. Ideally, the righteous medical personnel would include the know-itall mother in the child's rehabilitation, as suggested by the physician mentioned above, instead of seeing her as an irritant or threat. In this way they would be demonstrating acceptance of the PFCC rhetorical vision

The ideal PFCC vision would have the patient and/or family included in care planning meetings. By the time the patient receives a care plan, the medical team has already discussed the plan at length, and there may be little opportunity for the patient or family to revise the care plan until the following week.

The near character assassination of patient and family that occurred during these particular meetings was shocking to me as an outsider even though I realized that, in line with the consciousness-raising elements of SCT, such villainous we-they depictions were to be expected. Nonetheless, I was really uncomfortable with the conviction and intensity that team members had when they talked about pediatric patients and their families backstage. Such conversations between professionals may or may not illustrate the natural incommensurability of the traditional righteous physician-directed medical care versus the social PFCC rhetorical visions. Further study is needed to determine its effect. It is clear that more focused, hands-on training is needed to adapt the culture of some hospitalists into a mixed, righteous-social physician-directed medical/PFCC rhetorical vision. Without such training, it would seem that full participation in the PFCC rhetorical vision will remain the goal and not the reality

Therapy, care plans, and discussions were largely systems-centered. For the majority of interdisciplinary team members, aside from nurses and physicians, work hours were Monday-Friday daytime hours. This meant that some families that also worked these hours were not able to interact with therapists or administrators at all. The focus of the discussions centered on how team members were going to deal with the patient and family and not on how the system could support the needs of the patient and family.

Finally, physicians had the single greatest impact on how closely the team converged with the PFCC ideal vision. Even if the physician was extraordinary at transmitting the principles of PFCC to other physicians, they at times appeared overwhelmed by the consciousness-raising we-they talk (parent bashing or patient mocking) of the dominant righteous experts-know-best rhetorical vision.

CHAPTER 5: DISCUSSION AND RECOMMENDATIONS

Recommendations to Organization

The University of New Mexico Hospital

The pediatric hospitalists at the University of New Mexico do a respectable job of practicing the principles of PFCC. On the whole, they were considerate of the individual needs of each patient and their families. They took time to consider the social needs of the entire family and attempted at times to balance their own righteous vision about care for the patient with the concerns about the family expressed.

Physicians are clearly the leaders of any interdisciplinary teams, and their leadership greatly shapes the conduct of the group members in care planning meetings. It was not clear to me whether the physicians understood the significance of their leadership in interdisciplinary team meetings; some were more active than others in exercising such leadership.

Interdisciplinary groups were inclined to participate in a traditional righteous care rhetorical vision, which predictably, following SCT, resulted in we-they dramatizing depicting patients and families and caregiving amateurs as villains. Perhaps the members of the teams would share the more social PFCC vision if they were trained in the parameters of a mixed righteous/social traditional medical/PFCC rhetorical vision.

The inclination of the teams tends to be to vilify patients and families in their wethey consciousness-raising backstage talk; consequently, it appears necessary to rethink the PFCC training given regarding interdisciplinary teamwork. For example, the interdisciplinary team needs to identify the point of meeting together. Do they really need to check in with one another about what they are providing for the patient? What would the meetings look like if they were truly PFCC, so the patient and the family members were present?

Is it possible that the physicians do not value the social vision of the interdisciplinary meetings? Perhaps they view these meetings as another intense responsibility that does not really enhance patient care. Such a viewpoint may be understandable, given the amount of responsibility the physician has as a leader on this unit, not only for other physicians but for all patients, families, and staff.

The most significant revelation of this study is the overall dysfunction of the interdisciplinary team's seated rounds that I observed. These meetings sometimes lasted two hours, yet didn't appear to add much to patient care; such meetings may in fact have lasting negative impact on the care of the patient because of the vilifying that can occur. Further study is needed to ascertain if such an outcome is so. This organization really needs to ask itself what it hopes to achieve with the team meetings and to devise ways of monitoring how teams are functioning. The different disciplines represented in interdisciplinary meetings have no other way to connect, bond, and make sense of their experience other than through sharing of stories about patients and families. Even in groups where a clear template was provided, it was very difficult for the members to stay on track. The interdisciplinary team members are looking for ways to converge but may not be able to gather and communicate without resorting to negative conversations about patients and families. Of course, this may be a normal manifestation of a teaching hospital where medical school students and graduates are consciousness-raising about becoming physicians.

If the goal of the organization is to create interdisciplinary teams to take some of the responsibility for patient care off the shoulders of the physicians, this is not working, because the function of the group still depends on strong leadership from the physicians. It did not appear that these interdisciplinary meetings reduced work for the physicians, because doctors were still involved in every aspect of the patient care; they often followed up on the work of the other team members to make sure that care was being done properly. This micromanaging, combined with the dysfunctional, sometimes lengthy meetings, produced an ineffective and redundant process.

It may also benefit the GPU and Carrie Tingley inpatient rehabilitation unit to review its policies on patient pain management, as there were conflicting views amongst staff that could lead to under or overmedication of patients or professional conflict for staff. There was also a brief conversation between emergency room physicians where one was attempting to quantify how painful an ear infection is by saying he would rather have a toe amputated than to have an ear infection because the other physicians thought a pediatric patients tears were melodramatic.

The Institute for PFCC

The Institute for PFCC offers seminars or "institutes" to help improve PFCC using interdisciplinary teams. However, these are offered only on a quarterly basis, all team participants must be present, and the cost of the institutes is difficult to justify to hospital administrators. Often, a medical group can only send a team of four, which leaves an immense responsibility on those four individuals to convey what they learned back to others at the hospital. The literature that was immediately available via the PFCC website was very general and did not represent an awareness of interdisciplinary implications for PFCC. The Institute for PFCC should revise its materials to highlight the importance of interdisciplinary team participation in PFCC and provide guidance for organizations that is more readily available than the "institutes."

Finally, the Institute of PFCC has a highly social vision and may want to reevaluate its messages to professionals to make the concepts of PFCC more compatible with the righteous vision of physicians. Or it may need to direct its social messages to the interdisciplinary team members that are charged with providing social support to the patients and families. The Institute of PFCC would benefit from adding more righteous messages to the website and training materials that link PFCC to quality outcomes. Currently, the Institute for PFCC has almost entirely social messages and then makes an unsupported leap to the assertion that PFCC practices equal quality. The message to physicians must be something approaching "PFCC is the *right* standard of care" and must be delivered by respectable sources, such as pioneering physicians.

Perhaps this medical system has sought to address the PFCC ideal social vision with the institution of interdisciplinary teams comprised by staff who are viewed as having social jobs (social workers, psychiatrists, therapists). However, patients and families either want their physicians to be more social or need physicians to recognize support staff as important members of the team. The families are feeling "passed off" to the support staff, leading to the oft-expressed public notion that physicians are uncaring or do not have time to have meaningful conversations.

Future research

There appeared to be only minor representation of a pragmatic vision in the groups that I observed. Here, the pragmatic tended to surface in the we-they talk vilifying

insurance companies regarding the minimization of treatment. It may be that the administrators spare the other interdisciplinary team members the details of money and timeliness. In order to get a more complete understanding of the organization, it would be beneficial to observe business or management meetings.

It would also benefit the entire children's hospital to participate in Shields and Cragan's (1981) five-step process for SCT research, including analysis of the history of the organization, focus groups, interviews, the production of a Q-sort instrument, and market research. The focus of the study could be to produce organization-wide recommendations for training and protocol regarding PFCC. It could be interesting to test PFCC trainings that contain a mixed righteous/social rhetorical vision on physicians and might be beneficial to produce separate literature for physicians and other staff.

Another study that could address one of the limitations of this study would be to observe the frontstage and the backstage performances of hospital staff to determine if any of the characters or plotlines appear when staff interact with patients and families. Does the Stage 2 consciousness-raising of physician groups or interdisciplinary teams impact the delivery of care?

Finally, studying the impact of different physicians on the content of interdisciplinary teams may produce vital information about ways to keep meetings of such teams in line with the ideal vision of PFCC. Could the leadership style, ethnicity, or specific training in PFCC impact the function of an interdisciplinary group?

Limitations

One of the largest limitations of this study is the small amount of data gathered over a small amount of time. Another limitation of the study was the inability to supplement data gained from the seated rounds with data from researcher hosted focus group interviews that could have allowed participants to relate dramatizations of instances when PFCC is working well and when it is not. Further study is needed in this area.

Finally, although I made every attempt to protect against it, there is a possibility that my own bias as a parent influenced my analysis. I worked closely with Donald Shields, Ph.D. to check myself for bias but may not have been able to separate myself and my observations completely from my experience of being the parent of a child with intense healthcare needs cared for by some of the people that I observed. I also believe in the principles of PFCC and teach these principles to the hospital staff; I would like to see PFCC succeed in this hospital. That desire could be viewed as a bias potentially impacting analysis. Again, I worked closely with an expert who did not share my personal bias to guard against impacting the results.

The study's contributions to theory

The study demonstrated that elements of a rhetorical vision could be gathered and its convergence with an idealized rhetorical vision established through a fantasy theme analysis of the talk content of seated rounds using only field notes. The study led to the realization that in teaching hospitals, staff meetings included both consciousness-raising talk and talk illustrating acceptance and participation in the idealized PFCC rhetorical vision and the righteous Dr. Knows Best rhetorical vision.

The study illustrated that *we-they* consciousness-raising talk for medical providers at a teaching hospital is considerable and that it mostly occurs as a phenomenon of backstage communication. The study captured the existence of a new consciousnessraising fantasy type, used to vilify patients, parents, other family, and medical personnel, labeled the *amateur*.

Finally, this study provides a template for healthcare organizations to perform a fantasy theme analysis on workgroups to determine if the rhetorical vision of PFCC is active in the staff or if additional training is needed. This study may interest researchers interested in frontstage patient-provider interactions.

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Appendix A Glossary

Dramaturgy Terms

Backstage occurs away from the view of the audience (in this case patients and family members) and it allows the actor to drop the mannerisms or physical attributes of the frontstage role. In the backstage, individuals can be inconsistent, unprofessional, or vulnerable without fear of being penalized. Typical backstage scenes include conversations around the water cooler, in the workout room, in the lunchroom, or in this case, during seated rounds sessions. In this study, the backstage conduct is where the teamwork with other physicians is carried out and where consciousness-raising conversations can occur. This group, especially in its construction of characters (as predicted by SCT), made use of some powerful, villainous connotations about patients and their families as they engaged in Stage 2 consciousness-raising.

Frontstage. The performance of an actor before an audience. The actor knows that the audience is watching and is expecting a certain role to be maintained by the individual. In order to perform, the actor needs a scene to be present and a personal front which can be represented by a uniform or certain mannerisms that help the audience to believe the role being played. Ellingson (2005), proposed that physicians employ a frontstage code of conduct and a backstage code of conduct. The frontstage is the character of physician that is professionally appropriate and seeks to gain compliance from the patient.

Participant observation terms

Administrators. The term applied to staff at UNMH that are not involved in any clinical applications, such as social worker, discharge planner, patient liaison, caseworker, clinic director, and unit director. Although their backgrounds may be in nursing, rehabilitation, or medicine, if they are not serving in a clinical function and are charged with administrative duties as their primary duties, they will be included in this category.

Attending physicians. Bona fide physicians who are solely responsible for the care of their own patient load, instruct medical students during their pediatric rotation, and supervise residents and interns. They answer only to the director of their hospital unit.

Doctor/Physician. The terms *doctor*, *M.D.*, *physician or D.O.* will be used interchangeably throughout the field notes and the analysis of data and mean any person who has passed the New Mexico State Medical Board exams and therefore has the official designation of doctor of osteopathic medicine (D.O.) or doctor of medicine (M.D.). In addition to being referred to as a doctor, I will also be articulating their rank as an intern, a resident, senior resident, or an attending.

Family. The Institute for PFCC defines *family* as "two or more persons who are related in any way-biologically, legally, or emotionally" and is determined by the patients and families (www.ipfcc.org). The American Association of Family Physicians defines family as "a group of individuals with a continuing legal, genetic, or emotional relationship" (www.aafp.org/online/en/home/policy/policies/f/familydefinitionof.html).

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For the purpose of this study and to protect anonymity, family will be defined as any person, other than the patient, who is not a healthcare provider or professional.

Fourth-year medical students. They begin to specialize and spend the bulk of their year in clinics of their choosing, with the caveat that one clinic must be outpatient and one must be in the intensive care unit (ICU). They spend considerable time interviewing for residency programs that they will graduate into in the spring.

Interdisciplinary team. A term used to represent a group represented by some or all of the following disciplines: social worker, physical therapist, occupational therapist, speech language pathologist, nurses, respiratory therapist, health educator, Child Life staff (a division of UNMH that focuses on art and play for children while they are inpatients), and medical assistant. These are employees of UNMH that have direct patient and family contact in the clinic inpatient setting.

Interns. Individuals who have received their M.D. degree but are entering their first year of a residency when they have much more independent function as a doctor but are still under instruction and strict supervision of an attending physician.

Medical students. Those learning to be a physician. In this study, they are referred to as third year medical students and fourth year medical students. They practice medicine completely under the supervision and liability of an attending physician. Thirdyear medical students are beginning their first clinical rotations; the previous two years have been all instruction. The students rotate through seven disciplines for eight-week periods each: pediatrics, family medicine, psychiatry, neurology, obstetrics and gynecology, surgery (general and specialty), and internal medicine. *Pediatric patient*. Any person who is admitted to the GPU or Carrie Tingley inpatient rehabilitation unit and will typically be age birth to18 years. However, there may be some cases where an individual over the age of 18 may be admitted to these units because there is not the medical expertise for a childhood onset illness in the adult units or the patient has not yet transitioned to care on adult teams.

Resident. Residencies can vary in length, depending on the specialty, but the pediatric residency at the University of New Mexico is three years long. The term *resident* will refer to physicians in their second year of residency, when they have achieved quite a bit more independence but still report to an attending.

Senior residents. Health providers in their third year of residency who and have their own patients and begin to facilitate the seated rounds.

Specialist M.D. A physician who have completed their residencies and typically have completed a fellowship. Depending on the specialty, fellowships can last 1-5 years.

Therapist. This term includes physical therapists, speech language pathologists, occupational therapists, and respiratory therapists.

Symbolic Convergence Theory Terms

Chaining out. A series of successive excited or positive responses to a fantasy theme. This process builds a rhetorical vision representing a reality experienced simultaneously by the group as a whole.

Consciousness-raising (CR)stages. These are credentialing, polarization, new identity, and acting out new consciousness (Cragan, Kasch &Wright, 2009, pp. 53-55). Stage one, *credentialing*, begins with storytelling amongst group members that often

illustrate a heroic identity followed by others joining in and relating the story with stories of their own.

Stage two, *polarization* contains three types of *we-they* communication, which allow groups to build identity through polarizing relationships with other groups. *Upward we-they* has members of a group seeing themselves as less than or unequal to a group. *Lateral we-they* perceives members of a group as separate but equal with other groups. *Downward we-they* means a group considers itself superior to another group and therefore looks down on lesser individuals.

Stage three, *new identity*, is where group names, slogans, t-shirts, or bumper stickers are produced. This happens spontaneously and the group identity is not always related to the task. It could be that all of the members of a work group at an automotive manufacturing plant like to eat Gouda cheese. They may call themselves the "Cheeseheads" and not identify an association with the Green Bay Packers, nor is the team name a reflection of their work.

Stage four, *acting out new consciousness*, is concerned with preserving the identity of the group and moving the group forward. This looks different for different groups but can be symbolized by the band members circling to get "psyched" before a concert. Cragan, Kasch and Wright (2009) use the example of Japanese care companies whose "work groups in their manufacturing plants participate in stage four CR each morning before they begin their workday" (p. 55).

Deep structure. See master analogue.

Dramatis personae/character themes have to do with the people that are central to the dramatizing. The characters may be the actors in a play, a boss, or, in this study, the

characters may be the doctors, the parents, or the pediatric patients. The most common characters are "portrayed as heroes while others are villains" (Foss, p. 112). SCT formally refers to characters as dramatis personae.

Fantasy theme. A dramatized message it is the most basic and most important element of SCT and it serves as the agency through which SCTs other basic concepts (symbolic cues, fantasy types, and sagas) and all of its structural concepts (rhetorical vision, dramatis personae, plotline, scene, and sanctioning agent) are carried (Csapo-Sweet & Shields, 2000, p. 318).

Fantasy themes are the stories that individuals tell each other in order to make sense of some aspect of their experience. Participants in a rhetorical community come together and share these fantasy themes and negotiate a shared understanding of reality about the meaning of events, people, or places

Fantasy type. A stock dramatization "that explains new events in a well-known dramatic form, such as Watergate becoming Iran-gate or Whitewater-gate for groups of news reporters explaining new instances of governmental corruption and cover-up (Shields, 2008), or common scenarios that occur across time and cultures such as Nipplegate (When Janet Jackson had a wardrobe malfunction during a performance at a Super Bowl halftime show) being a clearly understood reference as a national scandal based on awareness of Watergate.

Master analogue(s): Righteous, social, and pragmatic. Cragan, and Shields (1981; 1990), whose research uncovered the concept of *master analogues*: social, pragmatic, or righteous, as the deep structure underlying rhetorical visions.

Righteous analogues. Underpin visions that have a clear right and wrong, moral direction, or correctness. *Social* analogues appear as humane, friendly, caring or service oriented. *Pragmatic* analogues stress practicality, efficiency, timeliness, or cost effectiveness. These visions compete as alternative explanations for symbolic reality (Cragan & Shields, 1981).

Plotlines. The action themes of the dramatization that focus on what the characters do. Examples of action themes in a medical setting may be a parent who eats all of the pediatric patient's meals or a nurse that never records vitals in the medical chart, making it difficult for a doctor to make an accurate report at rounds.

Reality-link. "Enables a viable rhetorical vision to account for the evidence of the senses and the authentic record" (Cragan & Shields, 1995, p. 46). Behaviors, events, communication, or outcomes that are inconsistent with the rhetorical vision of a group show lack of commitment to the vision. If a rhetorical vision lacks links to reality there is danger that the vision may implode because there is not the evidence to support the vision's retention (Bormann, Cragan, & Shields, 1996).

Rhetorical vision. The composite fantasies that catch up people into a common symbolic reality is a structural term that is the result of a large group entering into agreement about a common symbolic reality (Bormann, 1972). Rhetorical vision is "a crucial point in the transition from an impulse expressed by common expression by an aggregation of people that they form a special group with an clear identity and program" (Bormann, 1983, p. 74).

Saga, a comparatively late arriving concept in SCT research program conducted at the University of Minnesota, is the historical vision that an organization holds.

Bormann (1982) wrote that sagas are "the common symbolic ties that bind the participants to a formal organization and provide the symbolic aspects of the organizational culture and customs" and "a saga is a detailed narrative of the achievement and events in the life of a person, a group, a community, an organization, or a nation"(p. 53). Sagas may represent the lifecycle or history of an organization, or as Cragan and Shields (1995) indicate more broadly function as an "oft repeated telling of the achievements and events in the life of a person, group, organization, community, or nation" (p. 38).

Sanctioning agent gives legitimacy to the vision and are most frequently represented by "God, justice, or democracy" (Shields, 1981, p. 7; Blassage, 1999, p. 10). A sanctioning agent gives credibility to a vision and impacts the ability of a vision to be sustained or spread by containing "the most salient motives for action" (Shields, 1981, p. 7). In the PFCC idealized rhetorical vision powerful motives flow from the sanctioning agent of improved health care.

Scene. Themes about setting or *scene* are concerned with dramatizing about location. These themes may not simply be about the physical location but may also involve features of the location such as smell, the age of a building, or the location's proximity to some other structure. Setting themes, in SCT, are formally referred to as scenes. The description of a rival medical facility as Loveless denotes a scenic attribute.

Symbolic cue. A shorthand saying referencing a longer fantasy theme or dramatization such as an inside-joke. The symbolic cue phenomenon is illustrated in the introduction to this thesis by the reference to a "grandma." For a rhetorical community of medical students who have interacted with the attending physician, the referent to a

grandmother will be more likely to be linked with a person who is angry, difficult, or naïve instead of with a mature, respected, intelligent figure.

Appendix B Field notes

1 <u>Day 1</u>

- 2 I called Dr. at 8:15 am to find out where to meet her and what time to begin and she indicated that
- 3 she had just returned from a month in Europe and was "buried in paperwork." I arranged to meet
- 4 her closer to 9 am.
- 5 I began observation at 8:45 am in the General Pediatric Unit at UNMH with attending. She led
- 6 me into the "office space" with 6 workstations that lined the east wall of the room-the west wall
- 7 was lined with lockers. She introduced me to the one male and two female attending physicians
- 8 who were working on the middle three work stations.
- 9 Male attending told Dr. that he "yelled at someone and made them do math" (meaning one of the
- residents, interns or medical students). Dr. asked him if he had made anyone cry and and one of
 the women attendings said "not yet."
- 12 That same female attending initiated another conversation by saying "my patient is a huge wuss."
- The male mentioned the name of a patient and she said "no, that patient is not a wuss, he was justovernarcotized. He was just so stoned after his procedure."
- 15 The other female attending was talking to Dr. about how one of the residents had been on the
- 16 orthopedic rotation he had done his morning presentation on how to make moonshine.
- 17 Then the male attending told all of us "I'm going to give some feedback" and the female he had
- been talking with said "I think you like giving feedback too much" to which he replied "I think itis important to give feedback for improvement." agreed.
- 20 Next a discussion began about a young boy with cystic fibrosis who was afraid to go home
- 21 because he was afraid he would die if he went home. He finally asked if he could go home with a
- 22 pulse ox because he was afraid he was going to die in his sleep. And they had said sure so he
- 23 went home but the blonde female indicated that they had figured out that his bipap was set really
- really low by home healthcare so that was an explanation for why his condition had deteriorated
- 25 over time.
- 26 Then a conversation between attending and that attending began about how the mother-the blonde
- said "and then there was the mother" with a disgusted tone. "Once again! She said that she didn't
- want to make the decision[to put in a trach I think] until the tube was right in front of his face."
- 29 Then the blonde said something to the effect that the mother was cruel and then said "no decision
- 30 is a decision and its not responsible because it is going to mean a horrible, painful death for him."
- A moment later turned to me and said "nice kid, horrible mom." I asked what she meant by
- 32 horrible mom? Was she detatched or uneducated? She said that she just made bad choices and
- that he was not a candidate for a lung transplant and it was sad. They have been treating him for 8
- 34 years and its just sad. I asked why he wasn't a candidate and she said for lack of social support
- and I asked what that meant and she shrugged her shoulders. I got the sense that she felt like she
- 36 may have crossed a line telling me so much and decided to stop herself.
- **37** 9am
- 38 A resident, a medical student, a nurse, attending, and two orthopedic residents went into the room
- 39 of a 10 year old female. There was mention that the child had a lot of anxiety about wound care.
- 40 9:25 back in office space attending asked attending how the ortho kid did and she said "they were
- 41 going to try and work on a deep wound with out enough anesthesia so I stopped them."

- **42** 9:30 am
- Resident, Attending, two female interns, one male medical student, one female medical studentfor seated rounds.
- 45 3 MO male. Parents understand new diagnosis and seem to be doing well despite bad news.
- 46 CYFD had met with the parents to see if childs condition could be due to neglect. Docs did not
- 47 feel that this was a case of neglect but family does have 3 previous CYFD calls and father has
- 48 criminal record but waiting to hear back from social work for more information.
- 49 Attending asked that they clearly document how they instruct parents to feed the child and how
- and why because "a lot of times they will return for failure to thrive" and then it goes to CYFD asa neglect case.
- 52 14YO Female. Mom seems comfortable with child's PIC line.
- 53 7 YO Female. Grandmother is primary caregiver and reported concerns that seemed to be taken
- 54 seriously by providers. Child does not like people "Messing with her" so her breathing became
- 55 problematic during physical exam which grandma explained. Instructions were given to talk more
- 56 with grandma about how comfortable she is with taking the child back home and the 4 hour car
- 57 ride. On intern said "she scares me because there are not a lot of clues."
- 18YO F. "She's dong okay. She's a great drawer. She is starting at UNM for animation. Verycool."
- 60 9MO male. Don't know how compliant parents are at home with medicine.
- 61 10YO female. Dad and mom are in and out so need to prepare them for caring for her at home.
- 62 Can go home if she can tolerate packing and will begin discharge planning. Questions about
- 63 sending child home with Oxycodone. Medical students instructed to document exactly how many
- 64 you are sending child with in case parents abuse them.
- 65 14 YO male. Nurses can't pull PIC lines in GPU.
- 66 7YO male. Grandmother is primary caregiver. She reports that she feels comfortable with his
- 67 condition since he has been able to sleep. A conversation began about dosing for epilepsy drugs
- and talked about cutting pills into $\frac{1}{2}$ and $\frac{1}{4}$ and to call the nearest pharmacy that the family likes
- 69 to use to see what size of doses are available since UNM uses a small variety of sizes
- 70 3YO male. He has no problem ignoring doctors during exam (laughs). Family is Spanish
- real speaking. Dad was in this morning with child and asked if he had to wait for the nurse or if he
- 72 could administer medication. Mom had education but appears to have communicated it with dad
- raise since he was abreast this morning. There was a conversation about sending the kid home with a
- 74 medication regimine that required the parents to wake the kid every four hours for medicine and
- there was concern that that would be undo hardship on the parents. They decided to ere on the
- side of the protocol in recommending to parents.
- 77 3YO male. Need to question family for TB exposure. Comments about him eating too much. "He
- is a chunker" and "He could be anemic from all the milk and juice he drinks" were comments
- from dr.. It was established that he was likely just a straight forward case but they would do
- 80 some testing and "can pretend he is interesting."
- 81 4MO female. Mom reported arm movement but docs did not see it. Mom has reported symptoms
- 82 for 2 months and then doctor referred from rural city. Very big child. Talked about pulling some
- 83 labs while they do IV just to be sure. DR. recommended testing mom for drugs and medications

- since she breastfeeds. Male medical student would work with mom on ages and stages checklist
- 85 for developmental benchmark.
- 86 11:15 elevators a conversation began about interpreters and Attending said that if you don't use
- them then they are not likely to keep them funded. One of the interns said "I wouldn't even know
- 88 how to call one."
- 89 <u>Day 2</u>
- 8:15 am-beeping room-dr., 2 female interns, 1 female medical student, 1 male medical student,
- 91 led by female senior resident.
- 92 Female intern came in to room looking flustered-had overheard her having an intense
- 93 conversation in the office space with an older white male attending where she was unable to
- answer questions that he felt should be known by a person at her level of education. She is an
- 95 intern and indicated to the senior resident that she "had a confession. I did not get to see my
- 96 patients this morning." The senior resident asked her to go see her patients.
- 3MO male reported by female intern. Parents are not there this am and nurses said she hadn'tseen them last night. Intern will tell nurses to work with parents to facilitate feedings to make sure
- 99 they understand how to mix formula and administer feedings. "Don't' want to send him out and
- 100 have him come right back again [failure to thrive]. "Don't know if family will be here" Dr.
- 101 indicated that they had to be here and the nurses needed to observe the parents mixing and
- 102 administering the feedings. "How much have parents been here" asked attending
- 103 "only seen them once" answered the intern.
- 104 "We know the child can handle the feedings and take what he needs with us feeding him but we
- 105 need to know that the parents can. They need to be here and administer all of his feedings for 24-
- 106 48 hours before we can plan his discharge." attending
- 107 "Family has complications-they have other children at home who are sick and the grandmother is
- 108 sick and apparently had to be taken to the hospital and only one car." Female intern
- "I understand but a child is a 24 hour job and they have to be here even if it is just one parent. Ithas to be done before discharge." attending
- 111 7 YO female. Female intern. Breathing was fine until "messing with her." Family rural and "we
- should do what we can while child is here." Debate about how other doctors would object to them
- 113 performing further diagnostics and they it was decided by attending that they had new
- 114 information that warranted further investigation. "grandma is so sweet. Reading berenstein bears
- to her all day. I want to read them too!'
- 116 4 MO female. Presented by male medical student. "mom wants to go home" (laughs from female
- 117 intern and squinty face was made by DR). Mom did not report any siezures today. Female intern
- indicated that she attempted to "test the waters with mom and grandma." Discussion began about
- 119 genetic clusters in Navajo population for focal seizures. DR asked intern if the family was Navajo
- and female intern responded that they were from Rehoboth and Dr said "yes but did you ask
- 121 directly if they are Navajo." The answer was no. The report shifted to a discussion about the
- 122 prognosis for the child following the discovery of a brain abnormality on MRI that they had only
- briefly discussed with the mother. Female intern indicated that she "did not want to lay out an
- aweful diagnosis but it is likely that the child will have" significant disability. Again, mother's
- desire to go home came up (described by intern as perseverating).
- 126 "Is something going on like a religious ceremony?" Dr

- 127 "Don't know." Intern
- 128 Grandma indicated that the child has a cousin that also has some sort of focal seizures pointing
- back to some sort of genetic link. "keep it in the family" dr said jokingly (laughs)
- 130 Attending mentioned that the child hadn't been diagnosed for two months and questioned why
- 131 mother didn't notice. Female intern said that "although they are not particularly young this is
- 132 mom's first baby and pediatric seizures are hard to notice." Dr responded that she knows but still
- 133 can't imagine why mom didn't notice The head resident said that "it is sad but she didn't feel
- 134 good about this baby" in her gut when she saw her. The female intern on the case agreed.
- 135 "Bummer. Hopefully she has a good outcome." Dr
- 136 The conversation seemed over but then Dr said to make sure that the family understands the
- 137 importance of Early Intervention. Female intern said that she had attempted to bring that up but
- 138 mom seemed hesitant but maybe didn't realize that it is covered by insurance or that they would
- have to travel. Then the head resident provided education to the med students about EI.
- 140 "Maybe she wants to get her home for a healing ceremony. I bet you that is what it is, why she
- 141 wants to go home so bad." Dr.
- 142 Male medical student steered the conversation back to mom and grandma and said that they were
- 143 great and wanted to thank everyone for the care they are giving her. (ahh. From Dr.)
- 144 "Make sure mom has prior auth for meds? Mom has to have medicine in hand when she leaves.
- 145 Can't plan on going to Gallup and just picking up the meds." Dr
- 146 [..transition before she goes home..] Dr (head nods)
- 147 Male medical student was dismissed to study for a test that he had to take in the morning.
- 148 21 MO Female. Female intern No parents in room. They had mentioned missing an optholmology
- appt this week but talk with the family and see if they can be seen by someone while here. Talk to
- 150 family about going home.
- 151 18YO female. Female intern. Feels fine
- 152 12 YO male. Female med student. "mom denies any history of eczema", "he and parents deny
- 153 smoking."
- 154 A discussion branched out about asthma:
- 155 "We treat asthma so often we can get caviler but remember that asthma kills healthy people all
- 156 the time. It is very serious so I take my time and I am aggressive in treating it."
- 157 "Asthma scares me. We had a kid who was 14 year old athlete who had shortness of breath went
- to PCP was cleared, went home and sat on the couch to rest and when mom came to check on him
- 159 he was blue. He went to ICU, emo and he died. 14 years old and a baseball player. Asthma scares
- 160 me." Female intern
- 161 "You should be scared." Dr..
- 162 2 YO male female intern. Patient sleeping comfortably next to mom. Ready to send home.
- 163 9 YO male female intern. Was sleeping comfy. A discussion occurred about the possibility of
- 164 coordinating with a specialist to see if two sets of imaging could be done at the same time so that
- they could expose him to minimal radiation.
- 166 The nurse had reported that the kid kept asking "can I have this? Is this food for me."
- 167 "probably because he has broccoli and couscous." dr (boisterous laughter).
- 168 Ended with a discussion about checking with mom about how a new feeding plan would impact
- 169 her and see what she wanted to do to make sure he was getting enough nutrition.

- 170 10YO male female medical student. Social work needs to work with home healthcare to make
- 171 sure that family has what they need when child is discharged.
- 172 7YO Male.Female intern. "Did mom press button for seizure" dr
- 173 "she does the right thing. She focuses on his safety first."
- 174 "Prescription is ready to be picked up at walgreens on indian school and tramway where the
- 175 family requested. Family is afraid to start the depokote if it is going to be difficult and if they are
- 176 going to have to fight the insurance every time." Female intern (j) [Something happened non
- verbally that I was not keen to but they all looked at each other and laughed]. Family also did not
- 178 want to do the carb restriction that neuro was recommending because they felt that the child lost
- weight. Need to check with family and do education because they felt that they were confusingketogenic diet with low carb diet.
- 181 "Its important [to start the depokote] but if they want to push they should know the family
- 182 concerns with that." Female internt.
- 183 Caregiver was called Foster mom, grandma and mom. No clarification of what her relation to184 child is.
- 185 She called walgreens and was told that they couldn't guarantee to have the drug in stock and was186 not willing to go to hiland pharmacy.
- 187 "I totally understand her ideas but there are plenty of other pharmacies and she will have to go
- 188 where the drug is. Sorry. But." dr
- 189 Care giver turned down an offer for the docs to call pharmacies.
- 190 "Discharge planning should make all the phone calls. We can help family but we shouldn't be
- eating up time calling pharmacies. That is their job. Then tell mom in 5 months 'you need to askfor a reauth'"
- 193 Finally mom indicated concern with phenobarb that it is making child zonked and she said if they
- send him home and he continues to feel that way then they will not give him the drug at home.
- 195 Neuro attempted to appease her by lowering dosage and they would check levels in a few days.
- 1963YO male. Female medical student. Mom was not happy with respiratory treatment [attending
- 197 shook head, female intern laughed]. Patient has had 5 procedures to get a sputum sample but have
- all failed because child fought and the one sample had blood so that is not usable. Attending said
- 199 she was surprised the mom is still letting us do it.
- 200 "mom encouraged the kid to eat for the first time." Female med student.
- 201 Conversation started about fungus and then attending said "that is why I didn't do adult
- 202 medicine." Then a female intern made the joke "that is the sole reason right?" (light laugh).
- 203 Then conversation returned to mom not feeling good about treatment and then all of the failed
- procedures and how they could see why she was getting irritated. Decided to ask mom if she
- wants to do albuterol at night to give her some control.
- 206 "He's being a 'jito'" attending to which female intern replied "no a chion-a cry baby" then
- attending told how her nephew is a chion because he just whimpers and her sister runs to him.
- 208 Then we went into busy office space. Attending pulled me into hallway to explain how she would
- 209 like interns to present info to ID patient, then stats to make sure they get bigger picture but they
- 210 don't do what she wants and the senior resident is not as stern in getting that done maybe because
- she is not comfortable.

- 212 We then walked to check on a new admit who has had 30 admits in two years. There was a lot of
- 213 confusion, walking back and forth and then attending told me that they get a ton of non
- 214 compliance from the teenagers. Then they have to refer the children to child psych for
- 215 noncompliance.
- 216 "this is going to suck up my whole afternoon. I can just tell." Dr. "what a mess" because the
- 217 reports on how much medicine and fluids she had received at another hospital were not clear and 218 the child was in crisis.
- 219 I asked attending about what type of PFCC training she does with third year med students and she
- 220 said that they go over patient centered rounding and then mostly it is about examples. Then they
- 221 work on it with the interns more intensely. She still wishes that the interns talked to the patients 222 and families instead of at them.
- 223 Day 3
- 224 8:45 am Break Room-4 attending physicians, senior resident, medical student, 2 interns (all 225 female)
- 226 Dramatizing began about a child not being able to undergo a procedure because the child had
- 227 received .2 of oxygen. One of the attendings said "What do they do with those sick fucks in the 228 ER?" (laughs).
- 229 Dr. from Neurology came in to talk to the senior resident and one of the interns.
- 230 21 MO female.
- 231 "mom says she is good." "close for the launching pad." "I didn't talk to mom about possibility of going home so she may be surprised" "that MRI sure was impressive, huh?" Asked resident to 232
- 233 make sure that mom is comfortable administering diastat and that the nurses educate her.
- 234 Conversation ensued about whether or not child life had a diastat kit, if the hospital had one, can
- 235 get one from the drug maker.
- 236 "I tell parents not to be running all over the house-to keep the kit with the diaper bag because that
- 237 will always be with the kid"... and you shouldn't be running all over the house when the child is
- 238 having one of these seizures. "And when they get to preschool and go to school there is a
- 239 different kit and paperwork ... "
- 240 7 YO male "He looks better, eating like a champ. Mom thinks not doing well on low carb diet." A 241 discussion ensued about the difference between the low carb diet and the possible confusion with
- 242 the ketogenic diet. Johnson told a story-I missed part of it- about the fact that the child had gone
- 243
- to another foster home and eaten only pancakes and then missed the end of the story so not sure 244 what the point was but I am assuming that it was that the childs seizures increased with all of 245 carbs.
- 246 4MO female. "That kid is going to be a problem" intern and Johnson had a discussion about how
- 247 mom has started to just focus her attention to the childs arm when the intern believes that the arm
- 248 movements may likely be at the very end of a seizure. "we are focused on (laughs) the eye 249 deviation."
- 250 "Really hot EEG (bleep sound and made a face that exposed her lower teeth and jutted lower jaw 251 out, corners of mouth turned down)"
- 252 9AM seated rounds in new room
- 253 Attending dr, female senior resident, 2 female interns, 1 female med student.

- 3MO male-presented by senior resident. Following talk with family about the terms of needing to
- feed the child under the nurses' supervision for 24-48 hours for dispo, the family showed up at
- 256 3pm and have done all feeds with no issues.
- 257 "Told them they need to stay to gear up to go home" resident
- 258 "Make sure the nurse documents that family has done all feedings because there is nothing in the259 chart."
- 260 7YO Female, presented by female Resident. Child becomes agitated when touched. Resident
- reported that the the report from the diagnostic ultrasound was concerned that the child was
- 262 missing a kidney. Dramatizing "Two Kidneys" (laughs).
- 263 "I think she is regenerating them and selling them on the black market (laughs). " intern
- 264 "Grandma doesn't know she could be making more money." Intern.
- 265 "Grandma is kind of stoic (hand motion in front of face like scene change)," resident266 "but on top of it" intern.
- The presentation ended with the fact that the family is from Arizona in the fort defiance area and attending explained that the grandma didn't like the pcp because "he wasn't good at anticipating [child's] needs."
- 9:20 resident and med student left rounds to go and pack the wound of a patient. Attending andintern leading rounds said "so jealous."
- 272 21 mo F. presented by female intern (j). "Nothing exciting or fantastic has happened."
- 273 After intern presented informations, the other intern that spoke to specialist filled the group in on
- the dosing plan that she had for the child attending said: "I am going to have to write a veryspecific plan for the family"
- 276 Talked about prior auth. Family has no RX coverage-they will work with mom to get CMS
- 277 (Medicaid) or something. For now they are submitting requests to the drug companies to get
- reduced costs. Mom can afford Trileptol at Costco but the diastat is (\$300). The other thing had
- no answer and need to talk to pharmacy is to send home with diastat for breakthrough seizures.
- Again talked about making sure mom feels comfortable administering diastat (no specific talk
- about how to ensure that). Attending suggested a seizure handout. And talk about early
- intervention-"that will be up to discharge planning"-attending.
- 283 9YO male , female resident "little guy"
- 284 13MO male female resident. per dad baby has remained unchanged and restless overnight. Have
- to wait for dad to hold him to be able to work on him at all. Talked about pain management for
- him. Decided to stay with ibuprofen unless the pain got worse.
- 287
- 10 am med student and senior resident returned to group: "she was hilarious under sedation."(laughs).
- 290 7YO male. resident "spoke with grandmother."
- 291 "did you talk to them about carb restricions?" intern
- 292 "family was more asleep than awake." resident
- 293 "Neuro pretty insistant on carb restriction. Easy to follow compaired to ketogenic" intern.
- I asked for clarification because the words foster mom, adoptive mom, mom, birth mom, and
- grandmother have been used in reference to this case over the last few days. It turns out that it is
- foster mom and biological mom in the room.

- 18 YO f. resident-starting transition. Next admission will be in adult wing but will be overseen bypeds for maintenance of chronic condition.
- 299 12 YO M. med student "good kid. Motivated to get out of here."
- 300 6YO male. Resident. Was admitted because he had no received follow up care for a broken arm
- due to "social issues (laughs). I asked to clarify what that meant and they explained that the
- 302 family either didn't have transportation or mom works and only have one car and the hospital
- 303 records show that no arrangements were made for followup after the discharge so the child had
- 304 old pins in his arm that had gotten infected. Intern brought up the point that the child would
- benefit from PT because he has no range of motion.
- 306 "We will get social work in so they can arrange saferide or something and help them find PT."307 and they need to "stress to mom that this is important because-" attending
- 308 Then attending took over the group and said that they needed to find out who PCP is and let him
- know that plan and if they don't follow up then they need to be referred to CYFD because "this isa big deal if not taken care of."
- 311 10YO Female. Looked at pictures of childs wounds that medical student took with smart phone.312 "ow, gross" attending
- 313 Decided that with the girls anxiety around the wound packing that she cannot go home until that
- 314 gets better because she is requiring a ton of drugs that cannot be administered at home.
- 315 "Is childlife in there[procedure room or her room at all]" "no."
- 316 "She does better w/ dad or mom in there but most of the time is by herself."
- 317 It was decided that the family needed to be told that they needed to be present for packing.
- 318 3YO M. Med student. Nurses need to document that he has peed. Mom has been changing
- 319 diapers and tossing them but the charts have to show that he has gone to the bathroom
- appropriately.
- 321 "Mom feels comfortable with meds. She's on top of it." Med student.
- Attending/intern asked that she make sure she is comfortable and understands the importance ofmed compliance.
- 324 4MO f. resident. Discharge planning for early intervention. Talked to family about setting up E/I
- 325 but not extensive. They want to check newborn screening to see if it was normal.
- 326 10:40 convened and went to see patients.
- 327 Specialist in hallway-Male attending and female resident
- 328 It became apparent that mom had given pulm a different history than the history that was given to
- 329 GPU docs. "Its hard if she's gonna tell me.."
- 330 "one thing?"
- 331 "yeah." Mom had told pulm that child had no history that resembled anything like asthma
- 332 symptoms but had reported possible previous asthma symptoms with the admission of child.
- 333 "kina hard if they are gonna flat out (pause) lie to you" specialist attending.
- 334 "I just think mom wants to go home. And maybe will say anything to go.
- 335 "mom is worried about copay for prescription." F. intern.
- Then a conversation happened between the specialist team and the gpu team that I missed but the
- 337 gist of what I heard was that they wanted on one of the interns who is known to be proficient in
- 338 Spanish but the attending gently said no to the specialist team.
- 339 "They can call an interpreter. I don't want to lose you." Attending to femaile resident.

- 340 Specialist came back up to us after they spoke with Spanish speaking family and said that mom
- didn't know she was going home. The female Specialist resident said "perhaps it was my Spanish (hurdh)"
- 342 (laugh)."
- 343 11 am Radiology-woman specialist
- 344 Joke about "case of the missing kidney" (dramatizing about the ultrasound that resulted in a
- report that speculated the child did not have a second kidney.
- 346 Upon review of the childs ultrasound the radiologist said "this child is obviously aweful. Just
- 347 looking at the hips. Is she DNR?"
- 348 "No" "she's native" were responses from interns.
- 349 "grandma takes meticulous care of her" f. intern. The radiology said something to the tune that350 the child should be DNR regardless.
- 351 The next film the radiologist was emphatic about why the child still had pins in after an old injury
- 352 "Did the family give any excuse for no follow up?!"
- 353 "Family lives in Arizona, didn't have a ride.."f. intern.
- 354 <u>Day 4</u>
- 8:45 am in the break room, I was asked about what I am looking for with my study and told F.
- medical student and female intern that I was trying to establish Dr. vision of care and to comparethat with what patients vision is.
- 358 A conversation about where the 4th year medical school student was going to apply and a
- 359 conversation about cardiac peds came up. "I'm terrified of cardiac kids." Attending.
- 360 9:02 am Beeping room-attending Dr, male senior resident, 2 f. interns, 1 female medical student.
- 361 Dr asked for feedback in planning didactic for med students and then a discussion about last
- 362 nights basketball game came up.
- 363 "Moving on to patient care." (laughs) attending.
- **364** 6 Week Old Male presented by female medical student.
- 365 Was struck by the way this particular woman says "subjectively, mom says" and "parents deny
- any fussiness." She often uses the words "deny" and subjective when reporting. Have notappreciated that with any other report.
- 368 "Mom seems to be aware of infection.." (laughter) It was hard to catch what exactly happened but
- it appeared that Mom had been instructed about the fact that the child had an infection, a very
- 370 serious infection and a couple of different doctors of various rank had tried to explain to them
- what was going on but mom was viewed as not being bright or being difficult.
- 372 During this conversation a code blue alarm went off which is a series of rapid beeps. When it
- 373 started, all of the docs got up quietly and headed down the hallway followed by several nurses. It
- turned out to be an accidental pull of an alert cord in a bathroom. When we reassembled they all
- 375 said "bathroom call!"
- We returned seamlessly back to the conversation at hand. There was concern that the child would
- not be able to go home so soon because they didn't feel that is would be safe to send child home
- 378 with "dual antibiotics and a mom who is having a hard time understanding the child's care"
- attending.
- 380 6YO male presented by (j). Brief conversation about the mothers need for formula to be
- 381 prescribed before discharge and it was determined that that would need to be handled by
- discharge planning.

- 383 It was determined that the child's glucose did not need to be checked as often as it was and then a
- 384 joke was made about changing it to "an actual spot check where the nurse decides when to do the
- check." F. intern.
- 386 "Make sure with nurses and be clear about titrating fluids because they don't do it often." S.
- 387 resident
- 388 23 mo female, female intern. Came from an outside emergency department that gave her a ton of389 meds (laughter as she listed them off).
- 390 "That'd make anyone feel not so good." Attending
- 391 "except for tachycardia (laughs) she is pretty good." I am assuming this is because of the high
- doses of drugs that affect heart rate and is a referent back to the initial joke about overmedicating.
- **393** "poor thing" s. resident
- **394** 18YO female presented by f. intern. Just needed to follow up and make sure mom had what she
- needed for her to do her at home treatment. Pulmonology did not feel that the patient should be
- allowed to be discharged and to finish treatment at home because they deemed her as
- noncompliant. Peds docs thatknow her felt that she was just excited about graduating but notnormally noncompliant and that doc is not her primary so they are set to release her.
- 399 6 mo male presented by f. intern. Needs a PT/OT consult and make sure they know about E/I.
- 400 "Parents were passed ooout." F. intern.
- 401 9YO Male f. resident "can we just identify him by what he doesn't have?" s. resident.
- 402 "lungs-no problem there" (laughter) female resident
- 403 Jokes about what the foreign body in his abdomen could be.
- 404 5day old male. Med student presented.
- 405 "social concerns" reported by nurse and lactation consultant that mom has panic attacks and three
- 406 unwatched siblings at home. Mom is worried about other kids and wants to go home today. Baby
- 407 has been fine over night. Attending instructed med student to get social work involved
- 408 "we don't know what's going on but we can appreciate mom is probably pretty scared" from s.
- 409 resident and then interns listed other possible reasons mom could be stressed-postpartum, on
- 410 Prozac, fourth kid, dad not in the picture, poor social support. They will call a social
- 411 worker/psychologist that might have resources. Psyche consult.
- 412 10:15 specialists came in and in reference to mom: "she only brought enough formula for a
- 413 week." Attending.
- 414 "parents needed a break yesterday, they are pretty exhausted."
- 415 11 am radiology-older woman
- 416 "not a normal kid" she saw from looking at his CT scan. Then a joke picked up about the foreign
- 417 body in his abdomen. "he's an oyster-making boy" attending.
- 418 "no bleed so he's clear unless its colon cancer"
- 419 "don't say that!" not sure which woman said it"
- 420 Then a discussion began about a baby that was brought in last night in respiratory distress and the
- 421 f. intern said something about the baby being fine and then coming in blue and the radiologist
- 422 said "blue is kind of a pretty color." There was stunned silence, and awkward pause and then on
- to the next film.
- 424 Finally radiologist referred to Lovelace Hospital as "love lost."
- 425 <u>Day 5</u>

- 426 Luckily I showed up early because one of the interns grabbed me from the lobby because they
- 427 had decided to start the seated rounds early.
- 428 We convened at 8:45 am in the 'other' room not beeping room. Dr was attending, 2 female
- 429 interns, 1 male senior resident, 1 female medical student, 1 male medical student.
- 430 Are we ready to continue our "trend for weird or interesting issues?" attending
- 431 "calcium" sen. Resident
- 432 "more puss" medical student
- 433 "(knocks on wood table) no seizures." f. intern.
- 434 6 WO male mom switched rooms and is in a quieter room and is happier. Spoke with her
- 435 extensively about what is happening and she seems to be okay with everything.
- 436 "this is a spectacularly interesting kid-which you don't want to be." S. res.
- 437 6YO male (j). Parents were not in the room this morning. Didn't get to talk with them.
- 438 Discussion about how much food he should be getting f. intern said: "mom has the impression"
- that she should be feeding him this amount. Attending felt that intern was going to need to clarify
- 440 with mom to make sure that she understood what he should be receiving.
- 441 "Last night he had a nurse that likes to give meds." Attending (laughter). She asked the intern to
- be careful about writing meds because even if they are written specifically just to give if the
- patient needs them it : "gives some nurses the freedom to give them whenever without consultingus."
- 445 "where parents here?" f. intern
- 446 "don't know" attending
- 447 "just different if parents are asking" f. intern.
- 448 23 MO female resident Parents have received asthma education today
- 449 A conversation began about contacting PCP and dramatizing occurred about the many attempts to
- 450 contact some PCPs and they will leave multiple messages and the PCP will not want to leave the
- 451 exam room to take the calls or will not return messages but then they get very angry that
- 452 hospitalists don't follow up. Attending said that she was going to ask that that be the resident
- 453 project to figure out a system to report to PCPs. There are so many variables that contribute to
- 454 why it doesn't happen but attending instructed residents to document, document so that if there is
- 455 a question or complaint from a PCP then there is proof that we tried. "I think the problem stems
- 456 from those cases where the PCP needed to be called and wasn't."
- 457 10 MO female. Presented by Female intern. After a conversation they were able to clarify the
- 458 child's diagnosis. Unclear if confusion came from medical system or from mom misreporting459 patient history.
- 460 During this time a general pediatric surgeon came half way into the room (his body was only
- 461 halfway into the room, door propped open).
- 462 The child he is consulting on "is screaming about something-I don't know what" g. surgeon
- 463 "Social guy. Gets upset when he is lonely" f. intern
- 464 "parents are in there. I don't know" surgeon.
- 465 When talking about the possibility of complications the surgeon felt that they were doing all they
- 466 could to prevent and what the attending was wanting to do was not going to ensure that he would
- 467 not get complications so he was discouraging it.

468 "He's just unlucky" attending. After the surgeon left there was a brief discussion about how they

- didn't want anything else to happen to the poor little guy and they wish they could prevent it butthey can't.
- 471 Then conversation returned to 10 MO female. The child has an infectious condition so they began472 a discussion about how the child could have received the infection.
- 473 "Clorhexidrine baths for the family" (laughter.) F. intern. Then a conversation began about if the
- 474 mom is a blonde, if Clorox baths, even when bleach is diluted would bleach hair which led to
- some discussion/ lamenting about how peroxide makes hair orange and how it had made some oftheir friends' hair fall out.
- 477 9YO male (j) grandmother w/ child. After a list of lab results she said "now all the other levels
- are going down (nervous laugh)." They were trying to treat one problem and more keep showing
- up. There was talk of a possible surgical error that resulted in the problem that the child is in the
- 480 hospital for. The surgeon that may have made the error is no longer in the state so they will make481 an effort to contact his office.
- 482 He's the "kid that doesn't stop giving us surprises." (laughter)
- Wanting to make sure they solve enough of the problems so "the family doesn't get lost to (in)followup."
- 485 "Its going to be a nightmare to send him home." S. resident. Because a lot of his drugs have to be486 timed, interact with one another, etc.
- 487 9DO male. Female med student. Mom has improved in breast feeding. Psych and social work still
- 488 pending. She wanted to keep the baby until social and psych has a chance to meet with her.
- 489 "I get it, we want him to be safe. But, is staying in the hospital gonna reduce stress for mom?" s.490 res.
- 491 "This is the rare kid that I want to send home with a pulse ox but mom has three other kids and
 492 might not be astute and able to keep up with the baby. Might need a beep to keep up with his
 493 condition." Attending.
- 494 "There is just no way of knowing [how she will care for baby] with four children and on your495 own. The concerns about mom is we don't know."
- 496 16 YO male f. intern. They indicated directly to me that they are having a hard time getting
- 497 history because it is coming from the teen and he is changing his story (I was filled in after an498 unclear inside joke).
- 499 13 YO male. Female intern. "Mom was passed out." There was a brief discussion about if the500 child was "developmentally normal" or if he spoke Spanish. It was no to both.
- 501 10:11 am. The doctors began rounding because reports were finished early. I followed them,
- remaining in the hall, attending spoke with a therapist in the hallway about young girl with leg
- 503 injury "her range is terrible" therapist.
- 504 <u>Day 6</u>
- 505 8:45 in the office space. F. intern and 4th year female medical student were talking about the
- med students frustration with social work regarding family where the baby is being kept inpatientonly because of social concerns for mom and her situation.
- 508 Female intern came in and 4th year med student asked if she and survived and she explained that
- 509 dad was mad and frustrated because nuclear had come in and told the dad one thing and then the
- 510 nurses told them another thing "which was wrong."He is just mistrustful and feels "like if you

- 511 have insurance you get treatment slower." He did admit to the intern that he has a bad temper and
- 512 feels like he is under a lot of pressure and kept wanting to take his son to Lubbock for better care.
- 513 "He's all good now."
- 514 A female neurology resident asked the female intern "Hows the anemia kid? Headache guy."
- 515 9:00am Beeping room. Dr, male senior resident, 2 female interns, female 4th year medical
- 516 student, and male 3rd year medical student.
- 517 4th year medical student commended the intern for how she handled the disgruntled father: "You
- 518 do really good at talking people down" to which the intern replied: "working at a homeless
- 519 shelter" helps with that kind of thing.
- 520 An extended conversation began, as we all waited for dr to enter the room, about letters of
- 521 recommendation, how one person who you don't think much about can have a negative
- 522 interaction with you the one time you are having a bad day and can then be responsible to write
- 523 your recommendation. Intern conceded that she felt so paranoid through her third year.
- 524 Dr. came in with a birthday cake for the senior resident.
- 525 f. resident was the lead.
- 526 6WO male presented by female med student. "should be judicious with lab draws" attending
- 527 Dr. came in to inform the team that they have a brand new anesthesia nursing team so she was528 going to restrict the number of procedures performed from 10 to three and would not be doing
- anything with the baby today.
- 530 Then they talked about a patient and made a joke about "mom thinks [child] can go home with an531 external shunt" (laughter).
- 6YO male presented by senior resident. Child is squirming like he is in pain. Mom says he looksuncomfortable. "there is something a little bit disturbing going on" s. res.
- 534 8WO male presented by female intern. Mom was noted in emergency department notes as going
- to the ER because she felt like her apt for the child with gastroenterology was too far away andshe wanted a second opinion. Mom will have to go to Presbyterian hospital to pick up films. F.
- 537 intern said that gastro didn't want to see her because they didn't want people using the emergency
- room if they didn't like when their appointment is. F. intern agreed and talked just to the edge of
- saying that mom was probably overreacting on how sick the child is and is stable. Dr. interruptedand said that the labs show that the child is clearly having some serious issues and explained each
- 541 of the many labs and what they point to which is renal disease. The f. intern corrected herself and
- 542 said that she agreed and would wait to make any more judgments about how sick the baby was
- until they got all of the results from testing done at the outside hospital.
- 544 9YO male. Presented by male medical student. "grandma was bedside nurse." He indicated the
- 545 CYFD had been notified because they family may not have been compliant with the child's diet.
- 546 Grandma is there with the child most of the time. The team continually made jokes about how he
- had a pearl in him or a rock with laughter because a large fecal ball was removed from the child
- the day before.
- 549 "I dare you to wear that around your neck" f. intern
- 550 "no way!" attending.
- 551 1WO male presented by female medical student. Psych feels like mom's issue is more one for
- social work rather than for them. Mom doesn't have social security number and the new person
- at admitting is requiring mom to leave the hospital and collect pay stubs, utility bills, and so forth

to apply for the Medicaid which used to be easier in the past and now adding more stress with allthis paperwork.

556 Medical student indicated that she felt bad to keep the child until social work saw mom but she

just didn't feel good. The attending made the point that if the child doesn't have Medicaid-which

they don't not sure they can even send them home because they have no way to get him theoxygen and pulse ox that he needs.

560 "As hospitalists, we need to think about what families go through when they leave here"
561 attending. She went on to talk about the activity that pediatric residents have to participate in
562 where they have to get themselves to the Medicaid office and have to apply for services without

using a car, a cell phone, or a computer and how enlightening it can be. Attending stressed that
doctors need to educate the families in the clinic and that a lot of times their coverage will lapse
and they don't know that they have to renew until they get admitted and then it is too late.

566 "You have to anticipate their needs" and a mom with 4 kids, questionable transportation then has
567 to enter the world of Medicaid. And then you have to think about the rural communities of new
568 mexico and you have families in communities with no pediatricians, running water, reliable
569 transportation, electricity, etc.

570 13 YO male. Mom made nurse quit poking him.

571 10 YO female presented by female medical student. Nurse had helped dad too much to do wound
572 care and he needed to prove that he could do it 100% on his own if they were going to discharge
573 the girl.

574 16 YO male. Female intern. She retold the story about how the family had been through an

argument with nuclear medicine and then the nurse told them some wrong information and how

be "wanted to go to Lubbock." Then she said that she had broached the subject with aunt and dad

about the suspected diagnosis and that it would require a lot of treatment and they might even

bare to consider relocating to Albuquerque and they seemed positive except he indicated that he

did not like all of the minorities in Albuquerque so if they did move here then he would

- box homeschool his son. The two Hispanic women on this team indicated that they were offended by
- 581 him.

582 Hallway 10:35

583 I broke away from the group for about 15 minutes to catch up with Dr. to see about if there were 584 other opportunities to see other communication and she invited me to attend the discharge

584 other opportunities to see other communication and she invited line to attend the discharge

planning at 11:30 am. She asked me about what I am doing with my study and I just said that I

586 was looking for vision about families and patients. She said that what she didn't understand is

587 why I don't go into the rooms and how she supplies patient and family centered care. I said that I

588 feel that by the time you get into the rooms you've already completed all of the groundwork for

589 PFCC. Another attending was listening to our conversation and agreed that she likes the seated

590 rounds so that everyone can get their stories straight.

591 11:17 we went to radiology. On the walk to radiology the discussion began again about the baby

who came into the ER for a GI consult. And again talked about how f. intern felt it was notappropriate.

Radiology was the older lady reading films again. She opened an image and right away just said

595 "wow. Not a normal kid."

596 There was a joke about another doctor that I did not catch.

- 597 11:34 I attended my first discharge planning meeting which included all of the attending doctors
- 598 on duty that day, a discharge planning nurse, a social worker, a nurse coordinator, a charge nurse,
- a rehab coordinator (I think) it was hard to get anyone to identify themselves.
- 600 13 YO male "nicest lady" attending
- 601 "very nice" social work
- 602 "talks your ear off. You hang up and she calls right back" dr " but she must have thought he [the603 boy] was really sick."
- 604 "She is so dramatic" dr. (boy and grandmother are from Georgia and the boy was at a boyscout
- 605 camp when he became critically ill, she is out of town and can't get to the boy or back to Georgia606 until June 25th)
- 607 7YO female. "Why missing so many medical appointments?" Discharge planner. There was not608 real answer made and the group just moved on.
- 4 MO female. Family is discharged with a printout of numbers for early intervention agencies inhome town. Hopefully mom will call and connect with E/I
- 611 8WO Male-"He looks like fetal alcohol a little. Haven't seen parents so I don't know what they
- 612 look like but he" doesn't look right. Unit nurse.
- Parents were supposed to be in the room to talk to the attending and nursing even told them shewas coming but they left anyways.
- 615 "I can understand mom being frustrated but I can understand [surgeon] too." Attending retold the
- story again about how GI didn't want to see the child because the mom was using the ER to get a
- 617 GI consult that was non-emergent.
- 618 Social work will get back with mom (Spanish speaker, no insurance, immigrant)
- 619 Then a discussion began about how some insurance companies pay flat rate for inpatient stays per
- 620 day. Dramatizing about insurance company-one company is said to pay a flat rate of \$900 per
- 621 day for and ICU stay which likely actually costs \$4000-\$10,000 per day.
- 622 Then there was a discussion about 16 YO male's dad who has now gained a reputation and she
- 623 reported that his mom is an alcoholic that lives in another state. They are concerned about the
- 624 resources his family has in their home town.
- 625 Meeting adjourned at noon.
- 626 <u>Day 7</u>
- 627 Dr, 2 female interns, one male medical student, on female medical student, and a male senior
- 628 resident were present. I was late because I had another meeting
- 629 9:30 am. Not beeping room
- 630 I walked in on a conversation about mom having complicated social issues and had told the nurse
- about recently getting out of an abusive relationship but they were unclear (attending and s.
- resident) if this was a new conversation or just a rehashing of a conversation that happened when
- 633 the baby was in the NICU. Female medical student said that she did some medical education for
- mom but used the f. intern female resident to help her translate.
- 635 "make sure she has a ride" attending
- 636 "always more stuff. We do everything..."s. resident
- 637 "and then they still don't show up for appointments" attending
- 638 Then they made a joke about Dr. nickname which had been Lopey Lopes but they decided to call
- her Lanye West.

- 640 13 YO male presented by f. intern. Mom needs to be trained to do CPR because her child is in
- heart failure and docs will work with insurance to send the kid home with an AED to try and curbhis sudden death at home.
- 643 "This is the kind of patient that makes me sad. Makes us all sad." Senior resident
- 644 16 YO male presented by male medical student. This is the family where dad has become

645 notorious for his anger. Female medical student chimed in and said that as long as dad has been

provided with information on the disease he has been good and "is happy about surgery anddiagnosis and is just ready to go home."

- 648 10YO female presented by female medical student. The child, upon discharge will have to start
- 649 physical therapy, followed weekly by wound care, weekly appts with infectious disease, weekly650 appts with ortho, and weekly with PcP.
- 651 "Poor kiddo" s. resident
- 652 "I'm thinking about her dad." S. resident

653 "He's fine if I'm open and honest. He just needs clarification that when plans change it isn't 654 because she is getting worse." F. medical student.

- 655 Infections disease came in-an attending and a senior resident. The only real non medical
- discussion that happened was to make sure dad can do wound care on 10YO female just being
- discussed and the comment was made by ID that she is a "dramatic patient."
- 658 5Yo female presented by female medical student just said that parents wanted to stay inpatient

because they were too afraid to go home with a drain coming out of the child's head.

- 660 "and that is fine" senior resident.
- 661 "she drew beautiful pictures in childlife today." F. medical student.
- 662 14YO female presented by female resident girl took a bunch of drugs but says it was only to be
- high. Mom found her by tracking the girls ankle devise (laughs). Mom found her high and took
- her to regional medical center and she was then transferred here. Not the first time she had taken
- 16 pills of antihistamine. Attending looked up the drug and it turns out to be a popular
- recreational drug amongst teenagers. The they talked about how accessible and affordable
- robotussin is for teens who are looking to get high.
- 668 "poor thing" senior resident (he seemed to be the only one that said anything remotely
- sympathetic. Mostly it was more of making fun).
- 670 She was clear that this was "not suicide attempt and just wanted to get high." Attending
- 671 "could have been a suicide." S. Resident (laughs)
- 672 "Because of these kids we have to sign for."sudafed. s. resident
- 673 10:30 am rounding. I waited in the hall but I could see in the room and see that baby was in the
- 674 crib and mom was in bed and didn't get up from bed when all 5 people walked in. no one sat
- down but there was also luggage on all of the chairs.
- 11 am we went to radiology but there really wasn't anything to see.
- 677 Conversation in the halls between male medical student and f. intern went back to 14YO female
- 678 with drug overdose and she indicated that girl had admitted to spice and weed
- 679 "so probably drug use" male med student "whats that thing-if they say one beer it means ten?"
- 680 11:30 Discharge planning meeting. Several nurses, social work, discharge planning and

attendings.

- 682 I gave a little request that they might start to nominate families to our Patient and family centered
- 683 care advisory council and explained the details.
- Then a conversation began about the Goodwill store on but then they mentioned that the hardest
- part about shopping there is that everything is sorted by color and not size and one of the nurses
- 686 pointed that that was for the ease of the employees to sort.
- 687 "They do hire the handicapped" said a middle aged woman who has some unidentified
- administrative job (she laughed mostly)
- 689 "disabled not handicapped!" said the mail discharge planner.
- 690 11:41 still no docs had come in so there began another conversation.
- 691 "How is that little autistic?" said one of the women and then the social work explained that the
- 692 child was named after Elvis Pressley's twin who died just after birth to which the male discharge693 planner declared "SHE NAMED HER KID AFTER ELVIS'S DEAD BROTHER?"
- 695 plannel declared SHE NAMED HER KID AFTER ELVIS S DEAD F
- 694 "and did you see his diet?" asked the nurse to the social worker
- 695 "coffee chips and fires" social worker
- 696 "definitely autistic" said a female discharge planner who added that she heard about an autistic697 kid who only ate pumpkin or zucchini bread.
- Kid who only ale pumpkin or zucchini bread.
 CO2
 Earth and a second pumpkin or zucchini bread.
- For the young man going home in heart failure there was a discussion about going home with an
- 699 AED vs. CPR training for the family
- 700 "if it was my kid I'd want it (AED)" said a nurse
- Then they compared an AED with a vest which is very costly, requires a rep from the Arizona
- company to come work with the kid. They decided to work on getting the AED.
- Then they got to the subject of the 14 YO female who overdosed and the older administrative
- 704 lady said "that girl needs a spankin"."
- Then the conversation went back to the 16 YO male with the dad who has now become infamous
- and the nurse and social worker talked about how that dad was mad, why he was mad because a
- procedure was delayed because there was a miscommunication between nursing staff and nuclearmedicine but that he was extreme and inappropriate to be yelling.
- 708 medicine but that ne was extreme and inappropriate to be yelling.
- "Hey, we diagnosed his kid! Don't know what he's so mad about!" said the nurse. Nurse felt that
- 710 kid was mortified by dad's behavior and mom (actually his aunt) was just blank while he was
- 711 yelling and didn't say a word.
- 712 "poor kid. Seems like such a sweet kid" said the social worker.
- 713 <u>Day 8</u>
- **714** 8:45 am in the Alley.
- 715 Walked into a conversation between the attending and two senior residents who were female
- about babies drowning at parties. One attending had a cousin who lost a kid because he had
- 717 gotten into the pool and no one noticed and he died. They said that there are so many people that
- 718 you assume someone is watching them but they don't. Then they agreed that if they had kids they
- 719 wouldn't want a house with a pool. One resident felt fearful because she has a two year old and is
- 720 looking at houses down by the river.
- Surgical attending came in to release kids for discharge. "Doesn't have gallstones so I don't know
 if I can help him."

- 723 Two female attendings were talking with dr. about going in to see a child and his family. The
- parents had said that they didn't know any of the doctors names which angered the two residents
- and dr. because she: "said 'Hello, I'm a doctor' and shook hands and introduced everyone!" dr.
- 726 "They weren't paying attention because they were too busy talking about his teeth." (laughs).
- 727 I couldn't see who was talking so I am not sure who said what in this part but one of the women
- 728 mentioned that the family had been "fishing" for backup about the "obesity and school thing" and
- they had threatened to call the news (I derived that the parents felt that the child had gotten obesebecause of the meals the child was being supplied with at school). One of the women (perhaps
- 730 because of the means the child was being supplied with at school). One of the women (perhaps 731 the same one) said." fine to talk about diet but what about your responsibility as the parent?"
- F. Family REsident said that the family is from the Espanola Valley and so is she and people like
- 733 that family give that region a bad reputation. "Sure, he is hard because of his delays..." meaning
- that the child has cognitive impairment which could be challenging but shouldn't be an excuse for the parent's reaction towards doctors.
- Then the other female resident brought up the fact that despite the patient's delays he had a
- girlfriend that he was telling the doctor about. "He's delayed so that has hard [to understand him]but talking without difficulty."
- 739 I overheard the other team (f. intern and dr.) talking about disgruntled parents: "Parents are
- frustrated because they saw two different neuros then was told to go to ER but don't know whereto go or who to talk to."
- 9:15 am Dr. decided to hold rounds outside in a shaded area in front of the pavilion. We were all
- seated on a curvy bench so it was very hard to hear and to see one another. This team is all
- females. 1 4th year student, 2 3rd year medical students, 1 family medicine resident, 1 pediatric
- 745 intern, 1 senior resident, and dr.. They were all very curious about me-much more curious than
- the previous team. I did my best to explain what I am studying without giving too muchinformation.
- 748 3MO female presented by female family medicine resident. "I walked in and the bottle was
- propped up in the baby's mouth." This began a discussion about not propping the bottle. The new
- 750 medical students thought the reason against it was because of lack of bonding but Dr. told them
- that it is actually because it causes cavities or "bottle rot." "Haven't you seen those 2 year olds
- 752 with mouths full of metal?" (laughs).
- 753 "I know it is crazy!" 4th year medical student.
- 4MO Female Family medicine intern. "mom was asleep and didn't want to wake up to talk to me.
- 755 Did she talk to you? (directed at s. resident). She feels more comfortable talking to you."
- "She said the dr. told her that the EEG was fine. Mom may have some receptive issues." S. res
- 757 "okay(rolled eyes and laughed)." Then the peds senior resident said that she thought social work
- had gone by but she didn't see any notes.
- 759 "I don't know what mom means by(missed it)" (laughs). Family resident.
- 760 "we just have to get records" dr.
- 761 "mom wants to go home" family resident.
- 762 7 YO female presented by 4th year medical student reporting that "dad" is staying with her.
- 763 "She is kind of "difficult." Said the attending.

- Then they talked about how fevers are actually better left alone unless the child is having other
- complications from the fever such as breathing problems or seizures. "parent's freak out with
- fevers but they don't always need to be treated." Attending
- 767 "nurses want to always treat fevers." S. ped residents
- 10 YO f. presented by 4th year med student. Just said that mom has a lot of questions that maybethey could answer during rounds.
- 770 I noted to a 3rd year medical student that this team had a ton less patients
- "for some reason that teams patients stay longer" (laugh).
- In the elevator back to the ward they asked me again about what I study and I talked to them a
- 1773 little about how I look at how professionals talk to each other about patients and families.
- **774** 10:15
- 775 When we got back to the GPU we started a discussion about translators and their use at the
- hospital because one of the patients was Nepalese so they were having to use a phone translator.
- They gave them a cool card so they can point to a picture of the bathroom or phone if they need
- to. I've never seen that before!" dr.
- I asked how often they use translators and how. S. ped resident said that they have Navajo,
- 780 Spanish, and Vietnamese in the hospital at al times they have video chat for Spanish and
- 781 Vietnamese and they use a company called Pacific for all others. She said it is hard to use the
- translators sometimes because the parents will say a big long thing and then the translator will
- translate back a two word statement so it is hard to know if they are giving you all the
- information you need. As we had this discussion, the family resident and the 4th year talked about
- the clinic that the resident works in in Northern New Mexico and how there are a lot of Asians in
- 786 Santa Fe and N. NM. She went on to say: "I thought I knew Spanish until I tried to talk to a
- 787 Cuban." One of the women said "Mexican Spanish is so much easier."
- 788 We ran into some Speech Language Pathologists and began talking about one of the babies.
- 789 "..so cute! Mom is really good about following all of the recommendations." 4th yr med. Student.
- 790 I thought it was interesting that they closed some doors and not others. I couldn't determine how
- they were deciding but for some reason it started to annoy me or insult me.
- **792** 10:30 am the ped. Resident had a conversation with the genetics dr. who was impressed by the
- notes that he received from the geneticists at Denver about this child's previous testing.
- I overheard the other team that I had been with previously talking about how their patient only
- eats poptarts. A female intern said that nutrition had told her to put cream cheese and jam on thepop tarts to increase protein.
- 797 When we got to the next room there was some commotion and the team was laughing. The peds
- resident whispered to me that as they were all putting on gowns and gloves they realized the
- 799 infectious disease dr. was in there without any contact precautions.
- As I waited in the hallway I heard a women who I think was a doctor saying aloud "Oh these littlechildren. Eat your heart up!"
- 802 A nurse who I had sat in Discharge planning came by twice and gave me looks like she was
- 803 wondering what I was doing and didn't recognize me from previous introductions. Finally as she
- 804 was already past me, without turning around she said: "What are you doing?"

805 I said I was waiting for the medical students and she said "oh, you look like you are observing." I

- said I was and she said "oh." She didn't say anything to me when we got to discharge planningthat afternoon.
- 808 11 am on our way down to radiology we ran into the pulmonology resident. Dr.said that they had
- a child who was having some breathing problems and wondering if there are anatomical issues
- 810 (laughs) "she has drug exposure."
- 811 When we were walking to radiology Dr. asked the family resident about her tattoos and if she
- has to cover them up (they are all over her arms, legs and chest) and she said that when she was a
- 813 medical student she did have to cover them and that they couldn't have any facial piercings or
- 814 color other than their natural hair.
- 815 In radiology we had the older lady again.
- 816 On the first set of films specialist said "this is so underwhelming."
- 817 Next we went to another room to look at MRI and CT images (Neuro). After reviewing the films
- 818 for an infant which had been sent from Lubbock, the team decided that the child's injuries were
- 819 consistent with child abuse so they were going to have to go and notify CYFD and the abuse
- 820 response team. I was struck by how calm and non-judgmental they all were.
- 821 The medical students asked Dr. how she talks to parents about Non Accidental Trauma "abuse"
- and how the parents take it. She explained that she just says that they are not accusing anyone of
- 823 anything but that the injuries can be consistent with abuse so they have to investigate and that the
- reaction was 50-50. Sometimes they go crazy and sometimes they just say okay. "I'm like 'aren't
- 825 you just a little angry?!""
- **B26** Discharge Planning 11:30
- Each of the attendings (3 female), 2 nurse discharge planners, 2 nurses, and a male care manager.They made a joke about the boy who had the fecal ball removed again. "the poop pearl" and "our

829 little oyster."

- 830 Reporting on 11YO female dr. said "fun history." Apparently the child had been taken to the
- 831 PCP who had sent the kid to oncology. Oncology dr. put the kid on antibiotic for an infection for
- 832 3 months and that was all he did. All imaging after the first visit with oncology showed a chronic
- 833 infection of the bone. The doc never referred the child to infectious disease or anything and now
 834 he left the state and the child was passed around and now will likely lose her arm. "..really, really
- sad and they are so nice so it is really sad."
- B36 Dr. talked about the baby with suspected abuse related brain injury. She said that at this time theycouldn't rule out child abuse but when she spoke to (social work?) that they decided they could
- 838 hold off on CYFD report and then explained the social situation. Child was drug exposed in utero
- and was placed with adoptive family immediately after birth but they were told they were getting
- a "normal baby" so the adoptive father is very angry. The adoptive parents are fighting often
- about how much care this child requires and that the mom is ignoring the 3 year old now. This
- 842 whole thing is a "set up for abuse which is unfortunate" Finally, dr. noted that the mom is dying
- to get out of the hospital.
- 844 <u>Day 9</u>
- 845 8:45 am "alley" Dr. and Dr. And 4th year medical student
- 846 Dr. told a story about a kid with a two week old head injury who had a hard time with anesthesia.
- 847 "Those things always happen in my sedations! The mom passes out or the kid gets anaphylaxis!"

- 848 "That is why you are there" said dr. . "other people couldn't handle it."
- 849 Male 3rd year medical student from my previous team was talking about an "osteo patient" I told
- 850 him that my dad had just been diagnosed with a bone infection and he said that they really hurt
- and it was hard to get people to understand how painful it is. I asked "to get the patients to
- understand or family?" He leaned in and whispered "hard to get the staff to understand." I asked
- if he felt they were under medicating her and he said yes. He said that he is interested in pain
- 854 management and would like to go into that field after medical school. "we have the drugs to treat 855 the infection and the drugs to help with the pain and we should be using them."
- 856 We went into beeping room. Female ped Senior resident, female family senior resident, 2 female
- 3rd year medical students, 1 female 4th year med student, 1 female ped. Intern. No attending atthe beginning.
- 19MO male presented by female ped intern. "no updates on who has custody" asked the peds s.
- 860 resident. The intern said no and proceeded to explain that the child has severe failure to thrive and
- a tenuous social situation and no one knows who has custody, who will and the parents are
- seemingly unable or unwilling to care for him. They are not there and have done one of the"cares" since his admission.
- The social situation is complicated by the fact that the child is in tribal social services whichmandates that Native American children can only be kept by native American foster parents and
- there are not medically fragile foster parents right now. "Check on him many, many times."
- 867 (laughs) family intern.
- 868 5YO female. "mom lost counts of seizures which is unusual because she is usually right on top of
 869 it" 3rd year medical student. Peds senior resident asked if the family care team had been notified.
- 870 "Mom looks good today but intermittently..." s. resident. She asked to the medical students to
- 871 contact the family care team who should be following all families but make sure that the872 specifically work with this family.
- 9:30 am a code alarm went off and everyone got up and moved very quickly to the hall. The pedsenior resident yelled to the nurses station "room? What room?!" but once we were in front of the
- nurses station we could see the contents of all of the conference and break rooms empty into the
- hall. Several doctors of various rank were already in the room assessing the 4 month old who was
- 877 experiencing respiratory arrest due to a seizure. The mother stood in the middle of the room,
- about five feet from her daughter and watched helplessly. The hall was full with medical students,
- 879 interns, residents and a few nurses that waited with crash carts and other materials. Once it was880 determined that she was stable we returned quickly to our seats. No one said a thing or reacted
- any differently.
- 5MO female presented by family resident. Severe failure to thrive. CYFD has been notified.
- 883 Social workers in Taos say the child can go home with mother with close followup. Mom keeps
- saying how bad she feels about the baby's condition saying "why couldn't I feed my baby?"
- 885 The senior peds resident leaned over to me and asked if I was "in on it" and I said no. She shook
- her head in disgust at the situation. It was established that mom got signed up for WIC for the
- 887 baby's food and she has reliable transportation. Attending arrived and asked the resident to make
- sure that she documents that fact that the mom has been shown how to mix and feed the baby so
- that if the baby comes back for failure to thrive or mom doesn't follow up on outpatient "then it

- is abuse" and to make sure to talk to PCP. Also asked her to "in a nice way say 'if you don't
- make the appointments we will call CYFD'."
- 892 Then they talked about how the woman's friend called and said that the husband was really
- 893 controlling and wouldn't let her eat or let her feed her baby. She spoke to a nurse but the nurse
- refused to document the conversation because she felt like it was illegal. They talked about how it
- is not illegal and they live in a part of N. New mexico that is "off the grid" so it is not surprising
- to family intern that he could be like that.
- 897 The senior pediatric resident again leaned in close to me and whispered that the friend reported
- that dad had threatened to kill anyone who separated him from his child."
- 899 "and they are still sending them home.."
- 900 Renal specialist came in to talk about 10 yo female who has a problem with arm infection. Renal
- attending said "I don't care if she has leukemia" (laughs) " No that would be sad if she did."
- 902 "She better not have (couldn't hear). This family has had enough to deal with. What a weirdo.
- 903 Poor thing" attending talking about the same female who was misdiagnosed and now is facing
- 904 possible amputation of her arm.
- 905 <u>Day 10</u>
- 906 Carrie Tinley Inpatient rehab care conference
- 907 12 people were present 11 were female
- Admin. took a moment in front of the whole group to explain that their conference may seem
- 909 chaotic but that patients are often there for a very long time and last week was difficult because910 there were "no therapists last week."
- 911 11YO male. "pretty rocky course" was first presented by the healthcare provider. She explained
- 912 that she had communicated with Children's Hospital of Pennsylvania (CHOP) because they
- 913 specialize in this child's condition. "They see a lot of 'these kids'." He has a sitter at all times
- 914 because he is at high risk for falls. "He's tough"
- 915 "Do they have cases like him at CHOP?" asked the Therapist
- 916 "They have children who die because of this." Healthcare Provider
- 917 "shall we allow for an 'autistic environment'" specialist
- 918 "We should pattern staff behavior" with what has worked for therapist which is to "tell him what
- 919 you are going to do, tell him what you are doing, tell him what you did" administrator.
- 920 Use the "least words-only one or two" therapist.
- 921 At this point an administrator chimed in and asked that starting with the conference next week in
- 922 accordance with the 2012 CARF manual that "cultural preferences" are clearly stated in each
- 923 week's team goals such as food or comforting in a cultural way.
- 924 "when does mom plan on returning?" therapist
- 925 "Her grandma died" healthcare provider "mom said ' I will try everything to be there but my
- 926 grandma is really sick'. But she is calling in daily and talking to nursing."
- 927 "He is safety concern and he is not really benefiting for physical therapy" therapist
- 928 "it will be interesting to see how he does when mom comes back. You know when someone you
- 929 love moves on so maybe his behavior is changing..." therapist
- 930 "No, this started a few days before grandma died" healthcare provider "probably he knows mom931 is not here."
- 932 "autistic type behavior" therapist

- 933 "I don't want to call it that [in his medical records]. What could I say?" administrator
- 934 "vestibular stim[ulation]" therapist
- 935 They spent about 10 minutes talking about a 'craig bed' which is low to the ground and tried to
- 936 decide if it had been assembled, if it was safe, if he could receive his IV treatments in it, if it was
- 937 safer than just having a sitter with him at all times and finally decided that they needed to see if
- 938 the bed was even there and what state it is in.
- 939 "I don't always trust the sitters" administrator
- 940 "No kidding" administrator
- 941 "mom said when grandma died she would relocate to Albuquerque" therapist
- 942 "not sure what she will do" healthcare provider
- 943 18YO male.
- 944 Specialist implied to the mom that a procedure to use titanium netting to repair his skull would
- happen in mid july which healthcare provider felt was highly unlikely in her experience. Dr.
- 946 extended a lot of hope to Mom that the procedure would drastically improve his condition but that
- 947 is "not our understanding from the kids we've seen" healthcare provider
- 948 "I called [orthopedic surgeon] and she answered the page, in Kentucky!" healthcare provider949 "Wow!" administrator
- 950 "He seems to be having 'storms' but mom thinks it is pain" healthcare provider
- 951 "I started to instruct mom in massage and talked to her extensively about how we needed to get
- 952 him to look to the right and now he is doing it" which lead the team to discuss that he is 'locked
- in" to his body and has no way to express himself but that he is likely much more cognitively
- 954 intact then previously thought.
- 955 "Mom is very not a glass 1/2 full-glass is all the way full with her son" healthcare provider and
- then the psych agreed and they talked about how they were doubtful about the progress she was
- 957 reporting and the things she was seeing her son do. His case was much worse than mom was958 willing or able to recognize.
- Admin. informed the team that dad caries the insurance until the child is out of school which he
- will probably not be out in the next year but mom being "a glass is full" has applied to socialsecurity.
- 962 "Not going to be better in 12 months. We know that." administrator.
- 963 His biological dad has been in to see him in ICU and maybe once over the weekend. Mom is in
- 964 court with another man over custody of her 4 month old child. administrator reported that "mom
- is guarded with me. But she thinks she is going to get lots of resources in home. That is notaccurate." administrator.
- 967 Mom needs an "[administrator] talk" which apparently a staffer to talk to her and set her straight968 about her delusions of the kinds of supports and resources the young man will receive.
- A talk about "real life and how real money works" said the case worker in confirmation.
- 970 5YO male "Biggest problem is he is kind of a tyrant" healthcare provider
- 971 "You have a ¹/₂ full attitude with this one!" said the specialist to healthcare provider
- 972 He needs a behavioral program because "I can' stand his screaming" (laughs) healthcare provider
- 973 "I tell him 'if you are not going to do that then you are not going home" specialist

- 974 "mom has no idea how to handle him" healthcare provider. Mom has mental illness and dad is
- 975 getting ready to serve her with custody papers (laughter). "We will want to have security ready
- 976 for when he does that" healthcare provider
- 977 "He is a different kid when mom isn't there. I hate to say that about someone's mom" specialist
- 978 "I really believe he is in danger if he goes home with his mom" healthcare provider
- 979 "I wrote that in my notes" specialist
- 980 Then they explained how the childs uncle uses negative reinforcement such as" if you don't do it
- 981 I will have them put the NG tube up your nose again." (nervous laughs).
- 982 "I would not want to be his teacher" specialist
- 983 "Mom is convinced that the child is going to a special school for engineering and math"
- healthcare provider
- 985 "Its like she didn't hear anything when we explained brain injury to her. Pretty clueless."
- 986 Healthcare provider
- 987 "Uncle ____ can get the kid to do whatever he needs" therapist
- 988 "How old is the uncle?" administrator
- 989 "20 or 25" healthcare provider
- 990 "He's wonderful-like a father" specialist. "but he has no socialization. Like a wolf cub" (laughs).
- He has had not preschool and has just been raised by grandma and grandpa.
- 992 "He has a lot of potential but he needs to change environments" therapist (laughs).
- 993 "think people must yell at him all the time because he doesn't even respond. "specialist.
- 994 "granparents gave the impression he was excelling" therapist
- 995 "No, uncle said he probably had some issues" before the head injury healthcare professional
- 996 Therapist intern described a competitive game to motivate the child to participate in speech
- 997 therapy.
- 998 "he's so competitive." specialist
- 999 Then started a 20 minute chain out about the mother. The pace got very fast and I had a hard time
- 1000 keeping up:
- 1001 "Mom has been belligerent when told to get out of the child's bed. She has been reported as
- 1002 'tweeking and twitching' by one of the nurses and dad says she is (pause) using meth."
- 1003 Healthcare provider
- 1004 "Oh, my goodness" administrator
- 1005 "I need to get a brief [on kids history] because I don't trust anyone in that room." (laughs)
- 1006 specialist. "His teacher has her work cut out for her.
- 1007 "CYFD is supporting the father in filing for emergency custody. Whether or not he will be able to
- set the boundaries with the mom remains to be seen. Mom does not know about that plan."
- administrator
- 1010 "Staff covering over Thursday needs to know mom is getting the news. Mom will react bad and1011 maybe manipulate." therapist
- 1012 Then there was a joke about how the kid needed to be exposed to a book between the PT and OT
- 1013 because all he has been exposed to is computer and tv.
- 1014 "mom does not know how to regulate herself" therapist beginning the conversation about mom
- again. "Dad lives with his brothers and is convince his brother [mentioned earlier] will help care
- 1016 for child. Uncle is excellent out of all the (laughs) people" therapist

1017 "mom was so inappropriate at the team meeting last week" healthcare provider and "has had

1018 security called on her. [A nurse] told mom 'where did you come from? We had no problems till 1019 you got here'" healthcare provider

Then the administrator who was sitting next to me and who is familiar with me looked at me very 1020 1021 stern and told me that the woman they were talking about was a nurse.

1022 "The mom had a visitor named _____ but [nurse] told her he couldn't come to visit because the

1023 boy's dad didn't want him there. They called security and security told her it was [nurse's] floor." 1024 (laughs) healthcare provider

1025 Joke about mom getting served again and how the dad wanted a friend to serve her so that dad 1026 could take the boy off of the floor. At this time a bunch of people started to leave.

- 1027
- 1028 "The mom booted people out of the room-now she is moving back with the grandparents"

1029 healthcare provider.

1030 "They need to give her a lesson in tough love." Administrator.

1031 On her way out the therapist said something to the effect of being sorry it was so wacky.

1032 I walked out of the hospital with the rehab director and she seemed like she was fishing but there

1033 was another employee from her staff in earshot so we kept it very surface but she gave the

1034 impression that she was concerned about what she had seen and heard and wanted to know my 1035 impressions.

1036

Day 11

1037 8:45 I walked unto the unit to realize that the team I am assigned to had started early. I came in 1038 mid conversation. Present at the meeting was a senior resident, 2 pediatric interns, a 4th year

1039 medical student, 2 3rd year medical students. All are females

1040

1041 6 WO Male

1042 Senior resident was talking about the difference between CYFD (child welfare) and tribal welfare 1043 and how CYFD is much more quick to respond and easier to contact but that they had no

1044 jurisdiction over tribal lands because they are sovereign nations.

1045 "CYFD's goal often much to our dismay...is to keep families together." Senior resident

1046 Senior resident informed the other women that they will probably have a fair amount of

1047 experience working with CYFD. Anecdotally she said that doctors that come to NM from other

1048 medical schools report way more non accidental trauma (abuse) than where they came from. On

1049 a personal level it can be hard to deal with [seeing abuse] and the decision is "out of your hands"

1050 to return the child to the family you suspect were responsible for the injuries. "You made them

1051 better, you healed them with your knowledge" and you know they are going back to the people

1052 that hurt them in the first place.

1053 Senior resident went on to talk about the fact that a lot of doctors get nervous around the idea of

1054 having to report someone because of what is at stake if they are wrong or it is uncomfortable

1055 "but if you don't there is a chance that no one will." She then told a story of a homeless family

1056 that she just though seemed "odd" who kept bringing their baby into the emergency department

1057 saying the baby was really sick. The baby looked and seemed fine but the parents (who had three

1058 more people with them) demanded admission and staff wondered if they were just looking for a

- place to stay. They were offered places to stay each time they brought the baby in but would oftenget kicked out for drug use.
- 1061 S. resident said that she called CYFD the first time and the family was counseled and supplied
- 1062 with resources. They were back 2 weeks later " and like you said [directed to the 4th year med
- student] the baby just looked dirty" and she thinks the second time that the child was placed in

temporary foster care.

S. resident recommended that they try to refer the dad to Ronald Mcdonald house or room so hecan get some food and maybe a shower.

- I asked for child's age to see if this was a child I had heard rounds for previously and s. residentfilled me in that this was a new admit who was being cared for by a 14 year old relative.
- 1069 Although no one saw it happen, because the child was in a different room from the 14 year old, It
- 1070 is believed that the child's hand was bit multiple times by a feral cat. The child came from a
- 1071 Gallup clinic that didn't feel comfortable treating the child so they had sent them to Albuquerque
- 1072 for admission. The cat got away and was reported to have been killed by dogs and thrown in the
- trash so could not be tested for rabies. There where laughs at this point in the story.
- Senior resident went on to say that mom has a one year old and that she didn't not even know she
- 1075 was pregnant with the 6 week old until she went to the hospital with severe abdominal pain and
- delivered the baby "so there is some question about mom's competence there." (laughs)
- 1077 "Dad told social work that the child watching the baby was 16"4th year.
- 1078 20 MO male
- 1079 "today is his birthday!" peds. Intern.
- 1080 Intern said that she wanted to test for a digestive disorder to see if that would account for the
- 1081 child's failure to thrive and the s. resident felt that it was unnecessary to do that because the child

1082 has been gaining weight since they have been feeding him. No decisions have been made on who

- 1083 will have custody of this child as there have been no sightings of parents since admission.
- 1084 "He's so cute" 3rd year
- 1085 "I'm sad for him with his little mittens on all the time" s. resident (laughs)
- 1086 5 YO female presented by 3rd year. Child had a seizure "exactly when mom says between 7 and
 1087 7:30" (laughs)
- 1088 "I saw it in the note "will have another one between then" s. resident
- 1089 They then talked about the possibility of having to do a trans-vaginal ultrasound to look for the
- 1090 cause of her seizure increases and s. resident talked about the fact that it would be unfortunate to
- 1091 have to do that to a five year old and that they would do it with sedation but it can make her
- 1092 family uncomfortable and they would need to be sensitive but "it will be fine, it will be fine." It
- 1093 will have to be done if her other tests come back positive.
- 1094 2 YO male presented by 3rth yr med student. "Mom wants to keep him on current pain control
- since it is new but is willing to change what we are doing if he has trouble this afternoon."
- 1096 "He ate 2 chips" (laughs)
- 1097 Later in her presentation, the senior resident told the group that sometimes the nurses "walk
- around with a napkin or piece of paper and record all of the ins and outs and then enter them all in
- 1099 at one time at the end of their shift. So if you are looking and its like 'this patient has not peed in
- 1100 7 hours!' then you call the nurse to check. Sometimes they haven't peed in seven hours but..."

1101 "I didn't realize mom could pick foods for the child" 3rd year medical student after a brief 1102 discussion about dietary plans for a picky eater. 1103 "You should probably have a discussion with mom about Popeye's chicken!" (laughs) senior 1104 resident [this child is a 2 year old with gallstones likely due to poor diet]. "They don't always 1105 make the connection between something like Popeye's being unhealthy because they think 'hey, 1106 its chicken'." S. resident 1107 "I have biliary problems and juice makes me really sick so maybe we can tell mom that." 1108 Pediatric intern. 1109 "Since we can't really say that directly what you could tell mom is 'different people get sick from 1110 different things-most are from fatty food but some can be from juice or very sugary stuff." Senior 1111 resident. 1112 A conversation about how to control the child's pain began. "My pet peeve is how often we 1113 undertreat pain in pediatrics. I get it because parents don't want to just give meds. This just 1114 happened with my [infant] son where I didn't want to give him ibuprofen and then I was like-1115 'why am I withholding pain medication?!'" S. resident 1116 4th year interjected and asked how you tell families about when you contact CYFD. 1117 "you don't have to tell them you are calling. It is just based on your comfort with the family. 1118 Your safety is first and is paramount above everything else. Its just like in CPR when they tell 1119 you not to run into a swimming pool with a downed power line in it-well, that is a huge 1120 exaggeration but you get the picture. If you feel threatened then don't tell them." S. resident "I 1121 say 'Children, Youth, and Families has been consulted to make sure that you have all of the 1122 resources you need' instead of CYFD or 'you have a busy house so we will call social work to 1123 see how we can help make things easier for you'. Or I often say ' you want doctors to keep kids 1124 safe and be concerned about abuse' and that puts it on all people and makes it less threatening. 1125 11:30 Discharge planning. 1126 All female. One healthcare provider, four administrators 1127 The doctors were very late despite having been told that they needed to be more punctual. In the 1128 meantime one of the administrators began to talk about how "I am only interesting in anything over \$8 if it is something I can smoke and be happy." There was an awkward silence for a second 1129 1130 and then she laughed and said "just kidding!" Then she started talking about marijuana and how

- 1131 hemp plants grow all along the highway in some states and they use it for paper and rope and how
- she had seen some with her son but she explained that there are "many varieties of cannabis." In
- the conversation she used words like "marys" and "cannabis" with such great ease that it led me
- 1134 to the impression that she had extensive experience with cannabis. Then the conversation went to
- 1135 hemp milk, soy milk, almond milk, and rice milk. This same woman gave me names and numbers
- 1136 for other hospital staff that I can contact to get in on more rounds in the hospital.
- 1137 Finally at 11L50 the senior resident came in to present for her attending.
- 1138 Female patient-"family is doing well"
- 1139 Male-when we get his tests today we will have a better plan
- 1140 Female-"spent a long time with family today and prepared them to get plugged in to a slew of
- 1141 appointments."
- 1142 Male attending came in.
- 1143 17MO female-just moved here from Pennsylvania –"Welcome to hell" (laughs)

- 9YO Male-Family centered meeting planned for later in the week with CYFD and hospital socialwork .
- 1146 On the way out at 12:08 the administrator was saying to the administrator: "I wonder if his 12
- 1147 YO sister saw mom get black eye. Nice upbrining."
- 1148 <u>Day 12</u>

1149 8:30 am "the alley"- male s. resident and 2 female attendings were present.

- "Not to spoil rounds but I guess it is sort of a nightmare" s. resident in response to the mention ofa patient. "Mom and son are refusing to talk to psyche."
- 1152 The attending said that all they can do is document that they have made a recommendation to the

family to receive a psychological evaluation but if they refuse we can't make them.

- 1154 "So, he was fighting with his mom. Out of frustration, he picked up a piece of glass and started to
- chew on it which he admits to doing but then accidentally swallowed it. So, not a suicideattempt." S. resident
- 1157 "Oh, that's a totally normal 14 year old thing to do." Attending "can't make them see psyche
- though. Kin of unfortunate but all we can do is document that we offered. Teenagers do crazythings."
- 1160 "I did a lot but wouldn't even think about chewing glass!" s. resident
- 1161 I spoke with the male resident for a few minutes because he is preparing to move to Oakland for
- his pediatric fellowship. I asked if he read "The Spirit Catches You" and he said yes he had in
- medical school in Chicago. I said that it was interesting because he showed how real andcomplicated medicine and culture can be.
- 1165 "You know what stuck with me the most about that book? The one doctor that would send the
- 1166 women home with their placenta and he was the only doctor at that whole hospital that would but
- 1167 it wasn't because he cared. He didn't care at all."
- 1168 "So it struck you as funny or unfortunate?" me
- 1169 "I think both but I think it was terrible that the only person that did the right thing did it just
- 1170 because he was not a great person." S. resident
- 1171 Then the other attending started talking about 'bath salts' which is a new synthetic street drug and
- 1172 one of their teen patient had come in last night as a result of using them. They were trying to
- 1173 figure out the street name. I said that I thought it was K2 because I just read an article about a guy
- taking it and then biting his dog to death in texas. While I was talking an attending was looking it
- 1175 up on the internet.
- 1176 "Remember that baby that came in all high because the parents were putting a little bit of
- something that they bought at a smoke shop in each of the babies feedings in his bottle. The
- 1178 parents thought it would help his GIRD." Attending
- 1179 "oh no" the other attending.
- 1180 I asked the s. resident about if they utilize Child Life and his response was an emphatic "oh yes!
- 1181 We don't really ever have to call them because they are usually around. But they are great
- especially when we have a kid who we are having to give too much sedation to calm down. They
- 1183 are great sedation. Better than drugs in those cases. They just get in there and really calm the kids
- 1184 down."
- 1185 "They probably know the boundaries better than parents." Me

- "Yes, Parents worry about the leads following off and I tell them its okay, we can put them on if 1186 1187 you want to pick up your kid. A lot of parents are scared." 1188 "Yup, it is K2" interjected the attending I brought up the subject of the teen who had taken the 16 antihistamines last week and the 1189 1190 resident and the attending that were on that team affirmed. "skittles" said the resident. 1191 "she was looking to get high?" asked the attending 1192 The senior resident said that that is what the girl had reported. He and the other attending agreed 1193 that they didn't understand how teens can get a buzz off stuff like that or ketamine. 1194 "I don't know-when we are sedating some kids on ketamine they say the funniest stuff. I have 1195 never done any drugs ever but they are so silly that it kind of looks like fun." Attending. 1196 Then the resident told a story about a buddy of his who had called him one evening as he was 1197 passing through Chicago on a road trip and asked if he could stay the night. He had made a trip to 1198 Mexico to buy drugs that were not available in the US. "He had this huge bottle [hand gesture 1199 approximating a 6 inch height] of ketamine and he asked if he could store it in my fridge and I 1200 was like 'no!'" 1201 After answering a page a female resident who had just come into the room a short time earlier she 1202 announced to the group of us "got another renal kid." 1203 "groan." M. resident. 9am "beeping room" 2 female interns, 2 male interns, 1 male 3rd year medical student, one male 1204 1205 s. resident, and 1 female attending. 1206 7WO male presented by male intern with a thick accent of some Hispanic or Cuban decent. 1207 "Mom said he did well. May have colic." 1208 10 YO male presented by female intern. "parents worked hard not to have hi peeing in the middle 1209 of the night" s. res. And then she told the story about low urine output was low overnight. 1210 Instruction on presentation skills for presenting patient "You get sort of horse sense about what is 1211 important in assessment." M. res 1212 17 YO female presented by male intern. Girl has not been 'compliant with headache medication" 1213 and she seemed to have a "depressed affect." 1214 "such a pain when there is no specific complaint. She has everything!" m. resident " I have concern for anorexia because her labs are all over the place and she is very thin" m. 1215 1216 intern. "But, that is not what she came in for." 1217 S. resident asked him to reinforce to the teen that the way to avoid this problem is to take the 1218 meds prescribed previously. 1219 9 YO male presented by male medical student. "Mom and dad are bedside today which is good."
- 1220 "Epidurals are supposed to be great but in my experience they don't work that good" med student
- 1221 following a short description that the child's pain does not seem to be controlled.
- 1222 Then he described the surgery that the two surgery attendings were present at the surgery because
- 1223 it was such a unique procedure "Dr. (blank) was scoping and Dr. (blank) was exploring." Med1224 student.
- 1225 "Eh. Poor kid." S. res.
- 1226 "poor kid" attending
- 1227 11 YO female presented by female intern. "endstage CF"

- 1228 "Did not find that on her" (laughs) which I was in response to a negative test for some type of
- 1229 infection that can happen in CF but was described by attending as being "socially and morally 1220 deviated ing" a Basident
- 1230 devastating" s. Resident
- 1231 14 YO male presented by female intern. "So, he put glass in his mouth intestinally but he
- swallowed it on accident." (laughs). "No issues with anger or doesn't seem to want to hurt
- 1233 himself" so she felt like a psyche consult wasn't necessary.
- 1234 "Was mom there?" s. resident
- 1235 "Yes. Not sure if that is why" his answers are what they are. F. intern
- 1236 They then continued to make jokes about how odd the whole thing is for about three turns. Next
- they talked about how to explain things to look for when they send him home that would be
- 1238 complications of him swallowing glass.
- 1239 "It is very hard to explain to people what blood in poop looks like" s. resident (laughs) he then
- 1240 proceeded to give a detailed explanation about blood in stool and what they commonly mistake
- 1241 for blood in the stool. "I tell them if it looks like an overturned, potted plant and smells like the
- 1242 worst thing ever" then you might have blood in your stool. (laughs)
- 1243 "I debated getting psyche involved. Seems like a onetime thing which is why I want them to
- follow up with PCP. Seems good to his mom." Female intern. Social work is set to see him beforedischarge.
- 1246 "weird" male intern
- 1247 "odd" male med student
- 1248 11 YO female. Presented by female intern." Mom needs to learn how to change dressings [on1249 septic wound] and we need to watch her do it."
- 1250 4 YO female presented by female intern. "She [patient] told me I smell like bacon" (laughs)
- 1251 "only way to prove you don't smell like bacon is for everyone of us to smell you" (laughs) s.1252 resident.
- 1253 "positive bacon sign" male med student
- 1254 "I took a shower and I haven't eaten bacon in a (pause) while" f. intern.
- 1255 "At least her seizures resolve on their own. Not like [another patient] who goes apneic when she1256 has a seizure." S. resident.
- 1257 "would it be ridiculous to order a holter monitor?" female intern.
- 1258 "Yes. You would be laughed out of the program." S. resident.
- 1259 "then I will not" f. intern
- 1260 11MO male presented by male intern. Neurology is saying that seizure like episodes are reflux.
- 1261 "What do you think of neuros' idea's? " s. resident
- 1262 "Passing out seems severe for reflux" m. intern. Then the senior resident ran through the list of
- 1263 other symptoms of reflux and they agree that they haven't seen any other symptoms of reflux.
- 1264 "I think it is a little bit of a stretch for neuro to call it reflux" s. resident
- 1265 Then we took a turn and talked about reporting abuse. "the second the work abuse enters your
- head you don't necessarily have to call." S. resident.
- 1267 "Sometimes there will be suspicion in the ED (emergency dept) and you will see them order a
- 1268 huge full body scan and then you need to call." (laughs) "if you irradiate someone-you need to
- 1269 call CYFD" (laughs) s. resident. "I don't want to give bed legal advise." (laughs).

- 1270 18 YO female. Presented by female intern. "nursing says feeds were eradic but the parents seem1271 very saavy."
- 1272 An attending from specialty popped her head in and talked to male senior resident and the two
- 1273 female interns took this time to ask me about my study. I said that I was looking at Dr.-Dr.
- interactions.
- 1275 Seated rounds were over at 10:45 am and we headed to the special care wing to begin the family
- 1276 rounds. We waited in the hall for about 10 minutes for all of the interns to finish bathroom breaks.
- 1277 In that time the male medical student talked repeatedly about how he made guacamole, how he
- 1278 didn't know how it turned out because he is from the Midwest.
- 1279 The female intern asked me more about my paper and I just said that I am just looking at dr-dr
- 1280 communication and the type of messages they are passing back and forth and she asked if she
- 1281 could see my paper when I write one. I said I plan on writing one but not for several months.
- 1282 On our walk from family rounds to radiology the s. resident started a conversation about how
- 1283 there were tons of Spanish speakers in Chicago so he got proficient in it. But noted that in New
- 1284 Mexico 9 out of 10 people speek Spanish.
- 1285 11 am radiology led by specialist.
- 1286 "this pattern is boring. I assume the head CT is boring too." specialist
- 1287 "Horrible lungs. Her CF is aweful" specialist
- 1288 "This is one of three kids who have CF in the family" attending
- 1289 "oh isn't that special. Geez louise" specialist
- 1290 Then there was a joke about the kid eating glass and specialist said "I don't get that one" seeming
- to mean that she doesn't understand why the kid chewed glass.
- 1292 "This MRI is awful. It is enhancing hideously. This is ickly" specialist
- 1293 11:30 discharge planning meeting.
- 1294 2 admins (female) attendings, female medical student, healthcare provider, 2 female admins and
- male admin. "[nurse]said _____ scared the crap out of him" social work "said he seemed like he
 had a seizure when doing a lab draw"
- 1297 "Why is telling you about medical stuff?" female attending
- 1298 Social work said they are still trying to get ahold of the BIA (Bureu of Indian Affairs) lady. They
- 1299 have called several times and no response and one of the group said the reason why is that she
- 1300 will only get paid if she coordinates care for an adult so if she does anything for the child she
- 1301 doesn't get paid. "I don't know if she is on board."
- 1302 "see what happens" attending
- 1303 17YO male. Administrator informs the group that he is a Mexican national who has CMS
- 1304 (childen medical services has some money for medical care for undocumented children). "He
- admitted that he would try to apply for self pay but since he is not legal he is not eligible for
- 1306 Medicaid. " administrator. "There is AMCI which give vouchers for substance abuse counseling."
- 1307 "mom knows about illicit drug use?" attending
- 1308 "yes" social work.
- 1309 "Dr. ____ was telling us about spice" (laughs) attending
- 1310 "CMS only does \$15,000 outpatient so if you need to do any major testing or diagnosing you
- 1311 need to do it while he is here." Admin.

- 1312 12 YO female. She was in foster care and they are not sure if she is living with "bio or foster
- 1313 mom" but she keeps running away and doing drugs.
- 1314 "12" (laughs) attending
- 1315 "Partying..." attending " and mom says 'I kinda wanna kill the friends" attending
- 1316 "Right!? But then she retracted!" healthcare provider (laugh)
- 1317 "Interactions with mom have been very bizarre. Almost seemed mom was intoxicated. When I
- 1318 was in there the whole thing was about not getting a wake up call. Guess she thinks she is in a
- hotel. She just keep saying 'I need to talk to the nurse because I was promised a wakeup call and Imissed my apt." attending.
- 10 YO female. "She is developmentally delayed so I can't get a good idea of what hurts. Kind ofijust whining today." Attending
- 1323 Then there was an awkward dead silence for about 45 seconds until a new conversation about the
- 1324 12 year old girl who is being wild started again with tons of laughter.
- 1325 8YO female "I need to talk to mom about the value of a PCP"
- 1326 11 MO male. Listed all of the drugs the child is on (laughter) and the fact that she is likely
- allergic to one of them (laughter)
- 10 YO female. A provoked dog attack- "The dog gave a warning growl but the child continued tomess with the dog so he attacked." Attending. Parents are in Houston on their way in.
- 1330 "They might need a place to stay" administrator
- 1331 "They have Tricare so they will have to self pay any lodging or travel. Those who have jobs can't
- 1332 get the that kind of care [referring to Medicaid]" administrator.
- 1333 14 MO female "Mom will go get meds and bring them back so we can double check them before
- we can discharge her. Apparently the nurse saw dad's family attempting to administer some typeof herbal drug." Attending
- 1336 "What is her relationship with father?" healthcare provider
- 1337 "Comes and goes when he wants." Administrator
- 1338 17 YO female "PCP took her off migraine meds because he thought they would be too addictive.
- 1339 My plan is to talk to PCP (laugh) about plan" attending
- 1340 14 YO male She tells the story of the glass chewing to uprours of laughter. "He got mad at his
- 1341 mom, broke a picture frame, proceeded to eat the glass but then accidentally swallowed it."
- 1342 Attending. "We offered them a psych consult and they denied it."
- 1343 "Just weird. Both are really flat and neither of them seem to think that it is very strange that this
- 1344 kid ate glass." Attending
- "They are self pay and are not citizens and are not eligible for CMS so that might be why they aredenying any more services" administrator
- 1347 "Its just strange that they didn't think its odd." Attening
- 1348 <u>Day 13</u>
- 1349 8:30 am "the alley"
- 1350 "He's a pulm kid" female intern to male senior resident. Then resident makes a joke about the
- 1351 kids rhyming Hispanic name.
- 1352 I rode the elevator to the Emergency department with the male intern and the male senior resident
- 1353 to see who they talk to. There was a female attending in the ED "He had impressive retractions

- 1354 from this desk. We asked mom what seems to help him and she said 'just oxygen'. Okay" 1355 (laughs) 1356 At the ED desk a a male senior resident was talking to a female medical student about a patient they were about to go visit. "I've had swimmers ear and it hurts so bad. This year I had an ear 1357 1358 infection and a kidney stone and I honestly can't say which was worse. The kidney stone felt 1359 better right away because of the [drugs] (laughs). If I had to choose between the two I would 1360 rather cut my foot off."(laughs) 1361 It occurred to me that so far no one has talked about me being there. Everytime a new staff 1362 member comes on I have to introduce myself and explain my study. 1363 Back in "alley the female Pulmonology resident asked "Did that famly get the PIC ed and all that 1364 crap?" 1365 8:50 am beeping room Male 3rd year med student, 2 female interns, 2 male interns, s. resident 1366 and DR 1367 Female intern and male medical student asked me about study and then asked if they needed to 1368 sign anything. Next, they started a discussion about their political party and belonging to unions. 1369 "I signed up for a union and now I am trying to get my signature revoked" f. intern 1370 "They conned her into it." Female intern. 1371 "What do they even do?" med student 1372 "The fight for the well being of patients and docs. They fight for reasonable-ish wages. The 1373 represent our voices for patient care. They realized 'Hey, the patients are eating crap and we are expecting them to get better' and made the food better'" F. intern 1374 1375 "hours?" male med student 1376 "That's ACSME" male intern 1377 "Raise?" med student 1378 "We got it $\frac{1}{2}$ way through the year but it didn't match the cost of living" female intern 1379 "Mine was less than my husband." Female intern 1380 I asked the female intern if that was because of being a woman. 1381 "No, it is about being in pediatrics. We are all equal in here by gender. They just pay according to 1382 specialty. Pediatricians typically are the lowest paid doctors." F. intern 1383 "You just wrote that down didn't you?" female intern 1384 "yeah" me 1385 "do you record my name" f. intern 1386 "no. just biological sex and rank" f. intern 1387 "I want to be known as supreme being" 1388 "I prefer you to use my name which is . Not Dr." said the attending addressing the group. She 1389 also instructed the group to speak to the senior resident when they are presenting cases instead of 1390 talking to her so that he will be able to build his leadership skills. She said that she likes excited 1391 interactions so if they have read something or found some aspect interesting to please share it 1392 with the group so that they might all grow and learn from each other. "I might assign clinical 1393 pearls but we will see what comes up this week." "A lot of burns from fireworks?" m. intern 1394
- 1395 "Nice [interns name]. female intern
- 1396 "Lot of burn kids" dr "We already have some cool kids with interesting cases."

- **1397** 9:03 rounds begin
- 1398 11YO Female. Presented by Female intern who asked if Ortho would like to see the girl
- "My guess is they will-since they were following her (laughs) for a year" dr (they misdiagnosed abone infection and now the girl may not be able to keep her arm)
- 1401 10 YO male presented by female intern. "I don't know if Carrie Tingley does things different but
- 1402 it seems like they are not recording out units and only voids." F. inter
- 1403 "yes" s. resident
- 1404 "As long as we try to get it [MRI] before the weekend so we are not doing weekend discharge1405 planning" dr
- 1406 16 mo male presented by female intern. "He is just feeling kind of 'punky" x3 times
- 1407 "I'm kind of surprised that surgery wanted to biopsy the lung absess" (laughs) "because it could
- 1408 cause spread of infection or fistulas" (laughs) dr
- 1409 "Make sure surgery puts in a request to transfer his care to us." dr (when surgery peeked in dr.
- told him about this case and he said plainly "that's fine. Take him.")
- 1411 9 YO male presented by female intern.
- 1412 "I know him very well" attending
- 1413 "mom continued to refuse pain med but he has gotten morphine 6 x over the last 24 hours." F.
- 1414 intern
- 1415 "He is still anxious looking. Mother asked if he can get up and go for a walk in the wheel chair
- 1416 though he is nervous. Mom is encouraging him to talk to me." F. intern
- 1417 "CYFD meeting is this afternoon." F. intern.
- 1418 Infectious Disease came in (female resident and female attending) and asked if we had any
- 1419 patients they needed to look at "our 'lung absess'" (laughs)
- 1420 11YO female presented by female intern. She is "doing really, really remarkably well. Very
- 1421 friendly." Female intern
- 1422 "other than that just being an 11 yo girl."
- 1423 7 WO male presented by male intern. This case is "pretty straight forward" "about to be 8 weeks
- 1424 old so.. 7.9 kilos." (laughs)
- 1425 "We can give him immunizations on Thursday for his little birthday" m. intern
- 1426 "hopefully no osteo" dr.
- 1427 "oh god, I know." S. resident
- 1428 "This poor family. Mom has been there the whole time." M. intern.
- 1429 2 WO male presented by male intern. "mom wants to know how to switch pediatricians to one
- 1430 here. We are doing a fantastic job! And she keeps sking about circumcision (laughs) but I'm sure
- 1431 that would be better managed outpatient."
- 1432 "You can be a PCP now" dr "You can do it" (laughs)
- 1433 "Did it this morning. Bleeding a lot!" (laughs) male intern
- 1434 "Mom understands it can't be done here." M. intern after a few comments that that was not an
- appropriate procedure to be done inpatient.
- 1436 "I haven't done one since med school."
- 1437 "Terrifying." (boisterous laughter) m. intern.
- 1438 After he finished presenting his patient the female intern said, across the room "well done. Strong
- 1439 work"

- 1440 "Maybe I'll be doing his circumcision" (laughs) male intern.
- 1441 9 YO male presented by male intern. He has "profund autism" and "agitation increased when
- 1442 parents are around. They are excitable people. According to the nursed he does better when
- 1443 parents aren't around which is unfortunate."
- 1444 "I heard" (laugh) dr
- 1445 "Big kid though." M. intern
- 1446 "To reassure you –we all feel that way" dr said when the male intern indicated that he was
- 1447 nervous that the blood work was right on the edge of being dangerous and didn't know if he1448 should keep testing at the same frequency or if he should back off like surgery was
- 1449 recommending.
- 1450 "Dad. Oh, his dad." Male intern. "He is restricted between 2 and 4 pm. I don' t know how to
- arrange it because he wants to talk to the surgeon." Male intern
- 1452 "Get dad's number and give that to surgeon and he can call him" dr
- 1453 "I'm sure he would be glad to not have to talk to dad.' Male intern
- 1454 "He was nice to me but I think that was because he had been warned." Male intern
- 1455 "I read a letter on him." dr
- 1456 2 YO male presented by 3rd year medical student. "This is one of 9 children and he was a triplet.
- 1457 5 siblings have been adopted and 4 not. There is inactive TB in the home because 2 kids just
- 1458 adopted from Uganda" s. Res (laughs)
- 1459 "That's awesome" dr
- 1460 AT this pointed the same surgery attending from before peeked his head in the room: "If you
- 1461 guys are doing something with our patient let us know. He is on our service and we can manage
- his belly. I don't know why you guys are doing things with him." His tone was very angry
- 1463 "Sorry about that. There was confusion about whose service he was on" dr said very calm and1464 sincerely apologetic
- 1465 "I don't know if the nurses know but I am gonna reinforce it" surgeon
- 1466 Cardiology came in right after surgery and said that a woman with chronic health issues
- 1467 "probably has more services at home then she does here."
- 1468 Radiology 11 am.
- 1469 On the way the female intern and male intern talked to each other. "You rocked today" said
- 1470 female intern.
- 1471 "you rocked" male intern.
- 1472 I asked where the male intern was from and he said Missouri. He and his wife and two small
- 1473 children are here now.
- 1474 I then asked the third year if he had gone through the families as faculty program and family
- 1475 centered care training and he rolled his eyes. "yeah."
- 1476 "and no good?" me
- 1477 "eh. I mean. You get to see how other people live. But…" med student. 2
- 1478 11:15 am Specialist
- 1479 "I heard he had tb" "plus he is from the 'rez' so I would be worried." Specialist "looking here has
- 1480 [something that would indicate possible TB]" (cackles)
- 1481 "Just MRSA, don't worry about it!" specialist (laughs)

- 1482 "Well his oxygen saturation got better because we are lower elevation from after hours clinic"
- 1483 (laughs) (that clinic is 12 miles from the hospital)
- 1484 "ewww" said almost everyone at the same time when looking at the xray of a compacted belly.
- 1485 11:30 discharge planning
- 1486 3 attendings female, 2 admin, 2, healthcare providers
- 1487 One of the social workers was running late because she had been subpoenaed by CYFD.
- 1488 Apparently she got out early because a physician and social worker didn't show up to court.
- 1489 9 YO male- "ped surgery is primary, which they clarified" dr
- 1490 "So are they coming to CYFD appt?" admin.
- 1491 "Tell the [surgeon] I am happy to be here because I took care of him for 8 days. Its probably more1492 important if I am there" dr
- 1493 "Have you ever been to a CYFD meeting?" admin
- 1494 "no"
- 1495 "it is very structured so maybe we can have you do medical report first. It will go at least two
- 1496 hours." admin
- 1497 "Dad needed to be escorted with security. Not sure what happened." Healthcare provider
- 1498 "I guess he showed threatening behavior and he may be bipolar" dr referred to the letter that said
- 1499 he had been threatening and had shown 'hyper religiosity'."not sure who reported him"
- 1500 "autistic kid" administrator
- 1501 "He threatened his wife in the ICU" administrator
- 1502 "Yes, someone felt he threatened the wife." administrator
- 1503 "2-4 unsupervised?" administrator
- 1504 "I have this letter that should be in the chart if not already. I will email it to you right now." dr
- 1505 "When he was NPO they were feeding him snickers" administrator
- 1506 "mom is odd too" healthcare provider
- 1507 "Someone said she has autism" dr
- 1508 "I wouldn't be surprised." administrator
- 1509 "She's very odd-" healthcare provider stared to tell a story about the mom but was interrupted by
- 1510 dr reading the letter about visiting guidelines.
- 1511 "you can tell they care for him. Mom just makes odd statements" healthcare provider
- 1512 "They are at high risk. They have a really sick kid, maybe some mental health issues." dr
- 1513 "grandparents are wonderful." Healthcare provider "mom comes and we have to give the kid1514 atavan"
- 1515 "The parents are agitated by the resident that went in there" dr
- 1516 "Has siblings form Uganda...."dr
- 1517 "oh" administator "Never straightforward"
- 1518 "9 kids-he was a triplet, two sets of twins. Mom just had preme in NICU. Intibated." Healthcare
- 1519 provider
- 1520 "oh no" all together
- 1521 "It's a lot to deal with. They need a lot of help. All 6 and under" healthcare provider
- 1522 "I can't imagine" dr. "but doing great" "maybe we should keep him a little longer for social
- 1523 reasons."
- 1524 "give em a vacation" administrator

- 1525 dr was next to present 1526 14YO male "Going home today!" 1527 "yay!" admin in unison with another admin 7 YO f. "Grandma does very well with her. Never had an issue with her" healthcare provider 1528 1529 "mom can be here Wed. Mom is bringing in supplies." 1530 "Grandma said mom is coming in from Arizona. Grandma goes back and forth between family 1531 members' homes because some of the homes don't have electricity and running water." 1532 Administrator 1533 "That's no more confusing than others" dr "Grandma is pretty resourceful." They are going to get 1534 meds before they can leave." 1535 "confusing social situation" administrator "Tons of family has visited mom but no one helps with kids." administrator 1536 1537 "baby daddy' has been there"dr 1538 "skinny guy who could be native" healthcare provider 1539 "A big group of native people were there but she was fine with all of them" administrator 1540 "This baby dad involved. The girls dad is not" administrator 1541 "He was there at beginning" healthcare provider 1542 "Mom has clear delayed processing issues" dr 1543 "She is learning disabled" administrator 1544 "Didn't really come across that much.just quiet" healthcare provider 1545 dr was the next attending 1546 12DO male "make sure mom is feeding him enough" so she needs to meet with lactation. 1547 17 MO male CYFD okay with him going back with mom and dad 1548 "nursing staff noted family left with crib rales down and fork and knife and bubles in crib. Might 1549 be bad parenting" attending 1550 11 MO male "Mom Is very emotional, crying and crying." 1551 "Dad brought girlfriend and they are blaming mom that she is the reason the kid is 1552 sick."healthcaere provider 1553 "when dad comes in I will talk to him about girlfriend and she can't be there." 1554 "family blaming her for kid being sick" healthcare provider "she wouldn't say. Just said scary to be here." Attending "He looks good. His thing is just gross" 1555 1556 (laugh) 1557 "Can't we keep the cute ones?" administrator 1558 "mom fine with me but apparently tough to handle" administrator Meeting ended at 12:05. 1559 1560 Day 14 1561 Carrie tingley care coordination in the 5th floor conference room. 1562 Present: 4 female therapist, 2 male therapist, 6 female administrators, 1 female physician, 1 1563 healthcare provider female, 1 1564 "He is not Medicaid exempt. Hes on salud-mom said it was a big mistake. Don't you look who is 1565 qualified?" therapist to administrator before meeting started.
- 1566 "I can look" administrator

- 1568 understand how Medicaid works"
- 1569 9YO boy
- 1570 "Sleep hygene is very difficult for kids with this disease process." Healthcare provider "Mom is
- back from her grandmothers funeral and is pretty down about how we looks and that he doesn't
- 1572 seem to be getting better."
- 1573 "Is it time to talk to another facility?" doc
- 1574 "Talked to [doc at another hospital] who said we are doing all we can" healthcare provider
- 1575 "If we are not fixing him then maybe we should send him somewhere else." administrator
- 1576 Then the healthcare provideer told a story about a child with a similar illness but the docs missed
- the diagnosis for 2 months. Then they "threw everything but the kitchen sink at him" and he cameto us better then this kid.
- 1579 "He walked good but was 'ugly' looking" therapist "complains and whines when he doesn't want 1580 to do it." "5 months of this!" "I'm not gonna get a lot out of him. He has a wheelchair and he can 1581 stay in it." "Mom feels like he can do it. He doesn't like me. I had to hold him down twice for a
- 1582 procedure." "He is a handful and doesn't want to participate."
- 1583 "I saw him with mom present and it was the first time he wasn't moaning and growning. He
- seemed to really appreciate having her back. Mom talked with me about CHOP and she isfrustrated" therapist
- 1586 "As far as wanting to go there?" healthcare provider
- 1587 "Yes. I just listened to her." therapist
- 1588 "Problem is Medicaid. Since we can treat him here they will not send him." administrator
- 1589 "There are such things as comorbidities." Doc (referring to the possibility that the child is not
- 1590 improving because there may be some other illness at play that they have not diagnosed yet)
- 1591 "Mom wasn't planning on moving her anymore" therapist
- 1592 "You are too you ng for that" administrator to therapist-I didn't can't what caused her to say that
- 1593 "Mom has great fears about going back to ICU. I just listened" therapist
- 1594 (head shaking by administrator)
- 1595 "Definitely thinks he is not going back (laughs)" therapist
- 1596 "We deal with sad things" administrator
- 1597 There was a conflict between the therapist and the administrator over a popcylce. It was brief but
- 1598 the therapist was 'sharp' with the administrator-defensive.
- 1599 18 YO male
- 1600 "Mom thinks urination is causing rash and high blood pressure" healthcare provider (is taking
- 1601 mom's concerns seriously)
- 1602 "Head and trunk control is 'poor'" therapist
- 1603 "Definitely does better when mom tells him what to do." Healthcare provider (therapist laughed)
- 1604 I missed something about mom requesting something from mom and the therapist being
- 1605 uncomfortable with the request.
- 1606 "I think we are doing a great job. She is more interested than most moms which is great but if we1607 miscommunicate with her she could get mad." therapist
- 1608 "She does google and is saavy and if you want to do a treatment..."healthcare provider
- 1609 "She has a potential for 'teamsplitting' so we need to be careful with her." therapist

- 1610 "She demands excellence which is great. One nurse got mad because she was requesting one 1611 thing after another-" healthcare provider 1612 "As long as we are keeping her involved and listening then she is fine." therapist 1613 "We need to make sure to direct speech to him. Its her baby and she talks like he is younger but 1614 he is 18." therapist 1615 5YO male. 1616 "Tons of safety issues around that boy. He hasn't had an effective parent. Mom looks to me if he 1617 is doing something wrong. He can't go home for safety issues" healthcare provider "Dad hasn't 1618 been here so that is concerning. He is slated to go home with dad" 1619 "He says he is not going (laugh) good luck with that!" healthcare provider 1620 "Pretty behavioral" Healthcare provider (lots of laughs) "Is it possible to get him into a school or daycare program ASAP before school?" therapist 1621 1622 "He needs an IEP" admin. "Usually regular daycare won't take(missed-I think it was a hand 1623 gesture) so they want an IEP process" "He is currently running away from therapy" (laughs) therapsit "Mom uses therapy as babysitter. 1624 1625 She doesn't realize what Therapy is for" 1626 "Nuero psych" healthcare provider 1627 "Oh yeah-2nd grade" therapist "He doesn't need an IEP" healthcare provider mocking mom because she thinks child is very 1628 1629 bright "'I had an IEP"" 1630 "That child needs rules!" (laughs) "He does well with rules and structure once you break him in" 1631 His problems are due to "defiance and lack of exposure." "If we use bait we can move him 1632 through." therapist 1633 "That whole family needs so much..." therapist 1634 "structure" healthcare provider 1635 **at this point the conversation picked up and there were multiple comments happening at the 1636 same time so it was very difficult to tell who was talking to who, who was answering what. 1637 "DDwaiver kids? Do they get behavioral specialists?" admin. "Parents need training. 'rough shots'" healthcare provider 1638 1639 "CYFD offers parenting classes" doc "I could recommend. Mom is totally-" healthcare provider 1640 1641 "She is too doped up on her meds. She is never going to get it." Admin. 1642 " I went in and mom was on the bed and he was on the couch and I had to tell the mom that you 1643 can't be 5 steps away! It's not safe! I don't get that" healthcare provider 1644 "Safety vest?" Admin. (laughs) 1645 "Kid has great dexterity. He can probably get out" Healthcare provider 1646 "Yay" admin. 1647 "That child has so much potential" therapist "We can use an angel lock so he can't undo it." Healthcare provider 1648 1649 "He was shooting foam disks at me during our session." therapist intern (laughs)
- The was shooting foam disks at me during our session." therapist in
- 1650 "He has great motor skills!" therapist (laughs)
- 1651 "Grand mother was very emotionally upset and she took a long time." therapy intern.

- 1652 "They all have no filters. Talking about stuff in front of the boy they shouldn't. " healthcare
- 1653 provider (side laughs)
- 1654 "CYFD?" doc
- 1655 "They have visited the home. Dad and grandparents will care for him" admin.
- 1656 "Safety plans for them" doc
- 1657 Then there was about 30 seconds of side jokes about the family.
- 1658 13 YO male
- 1659 "He ran away from school" healthcare provider
- 1660 "so much for a right hemi" admin (laughs)
- 1661 "Dad says he is a lazy kid" healthcare provider Then she said something about having to hide
- 1662 pudding from him but he found some and the sitter tried to get it away and he hit her (laughs) and
- she couldn't get the pudding away from him. "Acted like [some previous patient]-out of control""call this puberty
- 1004 call this puberty
- 1665 "talked with dad for a while. Frustrated because of puberty. They live in the south valley so1666 school resources are no good. He's interested in out of district transfer?" therapist
- 1667 "I don't know the effort put into getting him better services at school from the family. A lot of
- his cognitive impairments are the same as my brothers (therapist) and they are the same age"therapist
- 1670 "Dad is depressed. DO you think they need a treatment foster family?" admin
- 1671 "they need respite. Maybe from Carrie Tingley Foundation." therapist
- 1672 "CTF has limited funds" admin
- 1673 "Not foster but services for respite" therapist
- 1674 "Isn't there only so much money for a year?" healthcare provider
- 1675 "CYFD offer respite?" therapist
- 1676 "I don't know" administrator
- 1677 "I think they've done a great job stepping into this situation with their skills" therapist
- 1678 After it was over I talked with the therapist about my understanding of some of the resources for
- 1679 respite that the social worker did not mention. I told her it was probably crossing the line for me
- to get involved but that I had a hard time connecting with respite for my kid and this family
- sounds like they might need a little extra help. She said that the social worker is not very helpful
- and she would personally make the phone call to the respite providers to find out what was
- available. I told her that I only used them for a few months just to get my footing and she said
- that is all this family needs.
- 1685 Then at 12 pm after the majority of people had left an impromptu meeting between a therapist
- 1686 and two admins. happened. An admin. had a format that she said they used to use and that they
- had really strayed from. "It needs to be family centered, team centered-Where do we neet to go,
- 1688 what do we need to do."
- 1689 "[healthcare provider] gives narrative report when it could be boom, boom" admin
- 1690 "Just the fact" (laughs) admin
- 1691 "Everyones story is a narrative" admin "Sometimes it doesn't matter if we have two or 10-it takes1692 us an hour"
- 1693 "Its okay every once in a while" admin.
- 1694 "I now. Like {patient name} is interesting but not on our service" admin

- 1695 <u>Day 15</u>
- 1696 I got to the conference room at 8:45 am and the groups had already started. I came into the
- 1697 conference room because I recognized most people in that group but there were two I had never1698 observed.
- 1699 1 male medical student, 1 female intern, 2 male interns, 1 male senior resident and one female1700 attending.
- 1701 I missed the female intern reports on her patients. As I walked in she was finishing up and then1702 went to the computer to input her notes.
- 1703 4MO female presented by male medical student.
- 1704 "Your husband is taking care of her" said a male intern to the female attending
- 1705 "Yes, I've hear a lot about (blank)" female attending.
- 1706 9YO male presented by male intern. "short gut kid"
- 1707 "surgery wants to sing off on him now" (laughs) [last week surgery was very angry at peds for
- administering care to the child]
- 1709 "Should we remove that medication?" male s. resident
- 1710 "I would say, since they are signing off (laughs)" attending
- 1711 9YO male presented by male intern. He said that the child needs to have two sedated procedures
- in the next two days and is trying to coordinate it so that they can do both under one anesthesia
- 1713 since they will need to be general anesthesia and that is dangerous.
- 1714 "Pretty big kid!"
- 1715 "No reason this couldn't be done" attending
- 1716 "It would be of benefit to not sedate him twice." Male intern. "he is very behavioral"
- 1717 2 mo male presented by male intern. "He's just hanging out. Only think keeping him here is the
- 1718 treatment we are giving but otherwise stable"
- 1719 "How did they catch this?" attending
- 1720 "Mom and dad noticed he was fussy every time they would change his diaper. Very astute" m. s.
- 1721 resident.
- 1722 "Yeah, it is very hard to catch and at that age." Attending
- 1723 16 MO male presented by male intern. "Aunt will have to receive education on PIC line because
- apparently she is the one who will care for her during the day."
- 1725 "mom is pretty 'with u'" male resident "was she crying when you went in there?"
- 1726 "no. she looks tired" male intern
- 1727 "When I went in she was on the phone and she was just balling." M. senior resident. "We'll keep
- an eye on her from a psych standpoint.
- 1729 6YO Male presented by male intern "he's very 'funny'" (laughs)
- 1730 Rounds ended at 9:45 am.
- 1731 <u>Day 16</u>
- 1732 10 am conference room
- 1733 I was not planning on watching the pediatric rounds this morning but I wanted to talk to Dr. and
- there was nowhere to sit so I hoped in on the end of her rounds.
- 1735 Present were female attending, female senior resident, female 4th year, female 3rd year medical
- 1736 student, female intern, and male intern.

- 1737 When I walked in the attending was explaining to the group that they should always check the
- 1738 meds when they get a new patient to make sure they understand what the meds are for and make
- sure they are accurate doses and are appropriate. "check meds no matter what neurology notessay."
- 1740 Say. 1741 10 VO
- 1741 10 YO female
- "great history of how she presented." Attending said to medical student who was about to beginpresenting the patient. "Did you get that history?"
- 1744 "I didn't" female 3rd year
- 1745 "You missed out" attending
- 1746 "Mom said she was born in Mexico and didn't present at birth but mom spent 3 months trying to
- 1747 figure out what was wrong. Finally brought her 'across' and in 9 days they had figured it out"1748 female senior resident.
- 1749 "Mom worried about treatment that she got last year. Mom said it was painful and not as
- successful as they had hoped. The doctors weren't happy with the post treatment results" female3rd year medical student.
- 1752 "She said that her glasses didn't work but when I asked her about them she denied a problem"
- 1753 female 3rd year. She then said "denied" 11 times in her presentation of the patient history.
- 1754 "physical exam is pure description." Attending instructing 3rd year on how to present
- 1755 "She had what you'd see in 95 year old grandpa eyes" (laughs) "nice kid by the way" attending
- 1756 "I made systems based plans but did it systems based with in her problems" 3rd year. (laughs)
- 1757 "We are trying to do two" procedures at one time 3rd year
- 1758 "wow" f. resident
- 1759 "Yeah! That's why she is so interesting." Attending about how she is presenting with bizarre
- symptoms. The 3rd year then said that she felt like Cystic Fibrosis could be very mild and not
- present until the person is much older and attending shook her head no and made a face. The 3rd
- 1762 year interjected that she had heard of a family who had one kid who was very mild and the other
- 1763 kid was always in the hospital.
- 1764 "I think I know who you talked to and may not be how they present." Attending (laughs)
- 1765 "Her diagnosis spawned from an ophthalmology exam!" attending. "I've been here a long time."
- 1766 "poor kid" whispered 4th year
- 1767 "Mom said last time tune up didn't work?" attending
- 1768 "Dr. told her that but not like mom thought she didn't feel good or anything" female intern.
- 1769 "That is mom's interpretation" but you have to make your own interpretation attending
- 1770 "The amount of intensity-as a parent-there is no way I could keep up with the needs of having a
- 1771 child with CF" (then she listed several ways that CF parenting was very difficult) "Its insane. So
- 1772 when they come in and non-compliant (laughs)" "It is really challenging much less when they are
- teenagers and they have to get up an hour early to start their routine. "So, when you are on and
- 1774 [patients mother's name] calls in the middle of the night you need to have patience." Attending.
- 1775 "That is why we look at the med list and make sure we know all she is on and why" attending
- 1776 "These CF kids get colonized with bacteria" attending
- 1777 "do CF kids have their own growth chart?" 3rd year
- 1778 "Someone has to be the 3rd percentile" (laughed) attending looked at 4th year
- 1779 "I was the 3rd" (laugh) 4th year med student

- 1780 "Did you see? That is why I looked at you." (laughed) attending
- 1781 "be tough on me because I only have two weeks" male intern
- 1782 "I'm not tough" attending as she put her hand in front of the face of the female senior resident.
- 1783 "I worked in Santa Fe for a year and let me tell you what you need to know-there is real basic
- stuff you will need to know- from personal experience. CF is not all that interesting for what you
- 1785 need to know. Managing asthma, bronchitis, and bilirubin, bilirubin, bilirubin, and bilirubin. Oh,
- and hypoglycemia in newborns and how to rule out sepsis. Mostly recognizing when you are out
- 1787 of your element. Depending on your nurses. There are some good nurses" attending.
- 1788 "the kid has my cell #" male intern
- 1789 "choose wisely" attending (about giving cell phone)
- 1790 "Why do they call it St. Victims" male intern (uncomfortable laughs)
- 1791 "I didn't run into that in the peds wards." Attending
- 1792 7 DO male presented by male intern
- 1793 "twice in a lifetime cases" attending
- 1794 "He is my sickest baby" attending" He has the potential to be the sickest so I've already seen
- them when we sit in here."
- 1796 "my plan for [child's name] if you don't mind" male intern
- 1797 "yeah" attending (giggles from all-I don't get what the joke is but it seems like there is something
- very funny going on between the male intern and the attending that I can't put my finger on).
- 1799 "They want us to do a rectal exam every four hours." Attending then she turned to me and said
- 1800 "not because we want to be mean but because it is therapeutic." (laughs)
- 1801 "make sure you wear a gown" attending to male intern
- 1802 "they say that is good luck" female intern then they broke out in ruckus laughter and continued1803 making poop jokes.
- 1804 "Test might be negative" male intern
- 1805 "Not gonna be negative" (laughs) attending "great case- and you get to do a rectal!"
- 1806 11 am Carrie Tingley care meeting in the 5th floor conference room
- 1807 Present were 2 male therapist, 1 female therapist, 3 female Healthcare providers (HP), 4 female
- administrators, 1 female specialist, and 1 female physician (doc).
- 1809 9YO male presented by the HP
- 1810 "how will we get the nurses to check his urine for blood?" doc.
- 1811 "it is bolded in my notes" HP
- 1812 "No one will look at that" (laugh) Doc
- 1813 "Then why do I even write it?" HP (she got noticeably red in the cheeks)
- 1814 "I think a note should be bedside" doc
- 1815 "He already has an order to dip urine" HP
- 1816 "how many times a day?"Doc
- 1817 "once but he wears diapers so they know what to look for" HP
- 1818 "You know if he gets someone different that they won't know what they are looking..." doc
- 1819 "Mom felt like being hooked to the feeding for so long was causing him to be more agitated." HP
- 1820 Shortening the feeds "seems to be working" HP
- 1821 Male therapist made his second reference to Christmas and the fact that his birthday was around
- that time. (laughs).

- 1823 "Mom is real appropriate with him" therapist Talked about the fact that he gets agitated and 1824 doesn't want to work and five others agreed. 1825 "Mom sounds like she is doing better" "She thought about (laughs) doing therapy so we went by 1826 the school and picked up a packet so that was good." therapist 1827 "Does she talk about how she is going to reintegrate him when he gets out?" admin 1828 "She doesn't even know what he is going to look like." specialist. 1829 "If he is the way he is now at discharge [I think she said she didn't know if] mom can manage" 1830 admin 1831 "She's got it in her to figure it out." therapist 1832 "She's not taking him home looking like that" doc "she's going to demand a transfer" 1833 "CHOP" administrator 1834 "That's what I think. She's already talking about getting" getting him out of here and going to 1835 another hospital. 1836 "CHOP is a good place" admin.. 1837 He's been here "5 months" HP 1838 "And just being a parent you want the best for your child and you want" to go where they can 1839 give him the best care and she won't just give up." Doc 1840 "[Specialist] needs to step up to the plate and talk to CHOP or whoever and see what is going 1841 on." HP 1842 "They need to come around and see their patients" doc and then she talked about a specialist 1843 resident who would come around and see patients in carrie tingley but that these attendings do 1844 not. 1845 "I have not seen any of the neurologists do it" HP (come around and see patients regularly) 1846 "Mom is looking for stuff to do to be involved so we need to provide her with some type of 1847 therapy she can do with him on the weekend." "We need to incorporate her in his care more" doc 1848 "Has her beliefs or disbeliefs about wheelchairs" Therapist 1849 "Each parent has their own thing on what works and doesn't. We need to show her we are really 1850 listening and we need to incorporate her more." Doc. "I don't know if it is safe for her to get him 1851 up and walk-" 1852 "Mom walks him independently" HP 1853 "I kind of bonded with mom. She is in a place she wants to do something for him." specialist 1854 "This was the first time mom wanted to hear any info about the [Medicaid] waivers so I want to 1855 thank the team because it has been a slow process I'm having with her." administrator 1856 "She's here all of the time now. No longer has a job?" doc 1857 "Family knows the people so not making her work" psych" that can only go so far." 1858 18 YO male 1859 "When is he getting his procedure?" Doc 1860 "some Wednesday" HP 1861 "What?!" Doc 1862 "I think July 25th is better then when it is scheduled in September." HP 1863 Joke by therapist again about Christmas and his birthday.
- 1864 "Forget about our patient and what they need!" said the doc when the HP explained that they
- 1865 can't do the kidney procedure at the same time as a neurological surgery because the kidney

- 1866 procedure is "dirty" and the doc is thinking that sparing the kid having to do a second anesthesia 1867 and surgery would be worth it. HP and specialist don't agree with the doctor. 1868 "Mom feels strongly that pain is associated with urination." HP "Pain patch is my fave." Doc "and this is another mom-get her involved!" 1869 1870 "You don't have to get her involved (laugh) she's right on top of it" HP. 1871 "Mom keeps telling me he can't move his knee because of [medical term]" HP 1872 therapist explained that the thing is not exactly the cause but kind of. 1873 "You are right [to doc] if we can make him more comfy we should. He's not getting benefit from 1874 therapy because of the pain so" its not like we will lose any therapeutic ground. Therapist "Its 1875 kinda of sad for me" (collective moans of sadness from throughout the room) 1876 "Mom seems to be starting to process this. She went to school to get a certificate to teach special 1877 ed so I told her that that will help her with her son and this experience will help her be a better 1878 special ed teacher. I just tried to encourage her." Therapist 1879 "She still said today that she is hopeful he will walk out of here." (laughs) specialist 1880 "Of course she did" HP 1881 "I need to start talking to the foundation because she lives in a two story house with no bathroom 1882 on the first floor." therapist 1883 "his mind is in there. Sad" specialist. "but his body..." 1884 "I need to talk with mom about her insurance and figure out the days of rehab and limitations." 1885 admin. 1886 "Gets 60 days and is at 30 and he can request more days through dad's employer." admin. 1887 We need to talk to them because mom and dad are not communicating." HP 1888 "They are going to mediation instead of court" don't know who said it 1889 "Most insurance once you have this injury won't drop you." HP 1890 "After [procedure] can we buy him some weeks by putting him in critical care?" Therapist 1891 "Lets do it. Get him another month" doc 1892 "We need to talk to insurance about this pain and other issues because he hasn't been able to 1893 rehab." HP 1894 "Hasn't been tolerating anything" Therapist 1895 "That's typical-they'll say" (laughs) doc "I asked if mom need team conference and she said no and that she felt like she had good 1896 1897 communication with everyone but if she is saying that she thinks he can walk out of here..." 1898 admin. 1899 Doctor to therapaist "Don't you think we should wait for the pain to get better and the three 1900 procedures ahead before we start making statements about prognosis-whether he will walk or 1901 not?" 1902 "Yes, still 3 procedures before we dash her hope" therapist 1903 "He's still not stable" doc so she doesn't want to tell mom he can't walk until he is more stable 1904 and his condition can be better assessed. 1905 "Specially with all his pain" therapist 1906 There was brief talk about a female being transferred from an outside hospital.
- 1907 2 YO male from Espanola, NM child was run over by an unmanned car

- 1908 "Low rider! That's how (laughs) it happened" HP collective uncomfortable, boisterous laughs
- 1909 erupted.
- 1910 "[HP's name] is not down with the brown!" therapist
- 1911 "It was ruled an accident" admin
- 1912 "Ranchos 5" (laughs) admin
- 1913 "So outpatient" doc (laugh) seems like this was dramatizing back to how the insurance is not
- 1914 covering the 18 year old until he is better and maybe about past problems they have had with 1915 insurance
- 1916 "Admit him on a Friday and we will evaluate him on Monday and drag our feet on the report so1917 we can buy him a week" therapist (laughter)
- 1918 "Don't write that down" doc (laughter) I laughed and then wrote it down.
- 1919 Then the HP said something about dealing with the mother of the kid that was coming from the1920 outside hospital.
- 1921 "We don't know what the mother from [outside hospital] is gonna be like. We are not here to
- 1922 figure her out but to get her kid better." Doc
- 1923 "Yes but difficult families can.." HP
- 1924 The members of the team all got up and began to leave.
- 1925 <u>Day 17</u>
- 1926 They were already in the beeping room when I came by and were working on a diagnosis for a
- 1927 patient before attending was there. Present were one 4th year med student, a female senior
- resident, a female attending, male family medicine intern, female 3rd year med student and a
- 1929 female pediatric intern.
- 1930 "I put out on the listserv so I wonder if the response is gonna be 'duh, its lime disease'!"1931 attending
- 1932 9YO female presented by male intern "Mom is gone. She had to go clean some houses. That's1933 what she does for a living."
- 1934 They talked about bundling procedures and that is why they have to do her surgery at 3pm1935 because of everyone's (doctor's) schedules.
- 1936 8DO male presented by male family medicine intern. "Parents got the umbilical stump"
- 1937 "oh, good" attending
- 1938 "yes, they plan to bury it in the horse coral as part of their religion. We found a hotel for the1939 grandparents" male intern
- 1940 He tried to decide if he should call a specialist to follow up on a treatment that she said she was
- 1941 going to start. "I wouldn't call [dr.s name]. If she said she will do it, she will. She's a busy
- 1942 woman" attending with agreement from the female senior resident.
- 1943 I had to step out to take a phone call so there is a pause in my notes. I came back in at 9 am they1944 were talking about a young girl with seizures.
- 1945 "Why would neurology wean clonopin when every time they wean her she has seizures?"
- 1946 (laughs) attending. "did she make it to her neuro appointment yesterday?"
- 1947 "yes, and had a seizure" s. resident.
- 1948 To the male intern "you can go do a rectal." Attending
- 1949 "Should I get a nurse or just stick my pinky in?" male intern "squirt sign; blast sign" (laughs)

- 1950 20 MO male presented by female intern ..."tied up in social work-two critical offices don't appear
- 1951 to be working together for placement."
- 1952 "tribal services?"s. resident
- 1953 "NO-in my notes essentially tribal court and then the office to approve arrangement. For moths
- has had foster mom who is a nurse. If he goes to [rural NM city] what I fear is then we have to
- 1955 establish 'medical home." Attending
- 1956 Then the senior resident did some dramatizing about when when she was a "sweet, wide eyed
- 1957 intern" and she had gone to the office that assigns logins to the state immunization database and
- 1958 they took one look at her last name and told her "nope. Not even going to try and find you a login
- 1959 with that name. sorry." They indicated that that was what had happened to the female intern in
- 1960 this group. "I hoped to get someone excited about their job and bright eyed..." s. resident
- 1961 "We will bop down to the clinic and be really nice to a nurse." Attending
- 1962 13 YO female presented by 3rd year female
- 1963 "She is easy to talk down" attending
- 1964 "I don't think it is for her parents" female intern (to calm the child)
- 1965 "She does have blood in the poop?!" female med student
- 1966 "I sat with them for an hour and a half and then she said she has had blood.." attending "I used to
- 1967 love when students would ask a question then attending walks in-what that displays is multiple
- 1968 people asking questions in similar but different ways." "Most 13 YO girls don't want to talk1969 about poop."
- 1970 "I don't poop" whispered female 4th year (laughs)
- 1971 "Maybe she thought just in her diarrhea." Female intern
- 1972 After a discussion of co-morbid possible conditions "that would be a bummer. Let's not give her
- two diagnosis" attending "We want the family to have faith in us. I told family that [east coastcity they visited] this is rampant." Attending.
- 1975 "Can we arrange her meds to better control her pain?" female 3rd year. They went through
- 1976 complicated med schedule and moved things around
- 1977 "[girls name] is so funny" attening. Then the attending told the story about how she had asked the
- 1978 girl what she wanted to be when she grows up and she said a cardiothoracic surgeon but now that
- she has been a patient she doesn't think she wants to be in the hospital that much. Attending told
- 1980 the girl that it is different when you are the doctor and not the patient. "I've been in the hospital
- as the doctor and the patient and the parent."
- **1982** 9YO male presented by 4th year female
- 1983 "Differencial gets broad when his lungs are full of water from the river" (laughs) attending
- 1984 "dirty river" 4th year (laughs)
- 1985 "Hope he gets a head to toe rash!" attending (laugh)
- 1986 "They didn't feel comfortable sending home from all of the social issues with oxygen." 4th year
- 1987 in regards to his previous discharge from hospital a week ago.
- 1988 "Are the parents smoking in the house?" attending
- 1989 "Yes." 4th year and senior res
- 1990 "I knew it" attending
- 1991 "Mom left excited about quitting and we set her up with resources but she is smoking."
- 1992 "Smoking is the hardest thing to quit, I've heard, but." Attending

- 1993 "Did you ask if they are smoking Marijuana in the house." 3rd year
- 1994 "I don't think we have any information to ask that." Attending
- 1995 "That's how he drowned-parents were smoking weed and drinking" female intern (laughs)
- "I knew they were intoxicated but not marijuana" attending. "CYFD has been doing weekly 1996 1997 visits."
- 1998 17 YO female presented by 4th year female
- 1999 "Everything [procedures] started on time" 4th year
- 2000 "woohoo" attending
- 2001 "I'm really impressed with her and how she is taking care of herself" 4th year
- 2002 "She had an 'aha' moment when she said 'I don't want to die" attending "thank you for doing
- 2003 the work-she's not." Attending (I don't know what this was refereeing to)
- 2004 13 MO male presented by female intern. While she was giving one line that introduces all of the 2005 issues the kid is here for the attending made a "pcccht" sound-of disgust?
- 2006 I had to step out to take another phone call and when I came back Attending was drilling the
- 2007 group about parent's names of each patient. "Maybe some parents don't mind if you call them 2008 'mom' or 'dad' but some do" She explained that she put mom and dad's names in the chart in the
- 2009 clinic so she can come in and say "Oh, hey---parents name" and even if she doesn't remember
- 2010 them they feel like she does.
- 2011 Meeting adjouned at 11 am.
- 2012 Day 18
- 2013 Alley
- 2014 "He's so much better than [dr. name] said." Attending to specialist regarding a patients cognitive 2015 abilities.
- 2016 In the hall waiting with group for attending female intern and male nurse had a nonverbal
- 2017 exchange:
- 2018 They looked at each other, then down the hall and laughed. Then he came back by and he leaned 2019 in and said "after you left she said she smoked spice."
- 2020 "No, I know! Don't know what to do with that girl!" female intern.
- 2021 9:02 beeping room Male senior resident, male intern, male 3rd year medical student
- 2022 2 MO male presented by male intern. "Mom concerned that she noticed [rash]" and she was right.
- 2023 Female intern came in and said: "[patient name] is in the hall and is saying she wants to go home.
- 2024 She's called her mom. Says we aren't helping he. Can you come in and help me?" She and male 2025
- senior resident left the room.
- 2026 While we were waiting they asked more questions about what I am studying (I have been with
- 2027 this group a couple of times). I gave the usual response and explained that this is actually to
- 2028 inform a measure and is not really the study but grounding work.
- 2029 Male intern came in and they started to talk about how the winter they would have 8-10 patients
- 2030 and how much more work that would be compared to the 5-6 they have been averaging now. One
- 2031 male intern told a story about a woman he knew who carried 16 patients through her program.
- 2032 "Can't even care for anyone if you have 16" male medical student
- 2033 Male s. resident and female intern came back in
- 2034 17YO female presented by female intern

- attach her heart rate shouldn't be so low. Have Psych see her." "We're good. I know somepatients can stress you out." "Its tricky when they are complaining of pain and they probably
- 2038 are.."
- 2039 "She needs to take her meds at home!" male intern
- 2040 "Atavan?" female intern
- 2041 "I hesitate. If she does and she gets a response then she'll want that every time." S. resident
- 2042 2YO male presented by male intern. "Mom wants to know how much he can do and how many
- people can come in his room." "There is a sign on the door that says no more than 2" male intern.
- 2044 "Probably want low stimulation." Senior resident.
- 2045 "She was like 'okay'" male intern. There was a brief conversation about weaning the child off of2046 methadone.
- 2047 Female attending cam in at 9:30 am.
- 2048 "He looks amazing for his injuries." Attending "mom brought up a lot of family members visiting2049 and there is only two allowed at a time. Asked her to let nursing staff know to enforce it"
- 2050 "she asked me that too and I saw the sign and told her two." Male intern
- 2051 "that's why she's asking. She needs help enforcing it." Attending
- 2052 6 YO female presented by male 3rd year med student.
- 2053 "Still in what seems like a lot of pain." Male 3rd year
- 2054 "Yes but had [this problem] before" attending alluding to the fact that this problem can't be acute2055 because it has happened before which means it is chronic.
- 2056 "Yeah, when I asked mom she said she's had this problem before." Male s. res
- 2057 "MRI-if nothing there then mom want to go to another hospital "male resident then they talked
- about the fact that they were sent from another hospital but that she was unhappy with the care
- thus far and had made arrangements to go back to that hospital if the MRI didn't prove the theorythis hospital was working on.
- "It sounded like she is going to stay. Her reaction was based on emotion but she wants to stay."Male intern.
- 2063 "The language in the notes made it sound like Mom was saying she didn't want anything to do2064 with UNM" male s. res
- 2065 "We will clarify with mom" attending.
- 9 YO male presented by male intern-nothing new or too much discussion other than a referral tothe feeding clinic.
- 2068 4MO female presented by male family medicine intern
- 2069 "Her child life book is complete so we will need to add any appointments we make."
- 2070 "There needs to be a 2-3 day period with mom mixing everything and staff observing to see2071 where we are at." Attending
- 2072 "She'll see Dr [name] which I'm excited about cuz she has no gauze and I don't know why or
- where it went." (laughs) male family medicine intern.
- 2074
- 2075 16 MO male presented by male intern "Mom is concerned about meds making him gittery"
- 2076 "Probably just so used to him just hanging out and now he's feeling better." Male s. resident
- 2077 "[Dr.'s Name] knows he's fired" attending (laughs) to male intern

- 2078 "He'd that go" male intern
- 2079 "He said it." Attending
- 2080 9 YO male presented by male intern. There was a brief conversation about the nurse who stopped
- 2081 feeds the night before and did not restart them so the child missed 9 hours of nutrition and how 2082 the nurse this night restarted the feed after only an hour and it was good.
- 2083 "Sorry for throwing that out there without knowing. Very unprofessional" was what the male
- family medicine intern said after he misquoted some fact. He apologizes ever ytime he says anything.
- 2086 8YO female presented by male intern.
- 2087 "Night team says mom in non-compliant. Mom was not here today." Mom wasn't in there and her2088 mental status-eh" male intern.
- 2089 "Haven't seen an asthma kid" male intern
- 2090 "It's a quality control measure for our asthma initiative-every time someone comes in and is2091 asthma kid it pops up on them [pulmonology] " senior resident.
- 2092 "I won't tell her or mom anything about today. Just hanging out." Male intern
- 2093 4YO female presented by male intern.
- 2094 "Mom is concerned about the way she is breathing." Male intern.
- 2095 "you will be the one reading your own xrays in one year" attending was telling them that they
- should really take the time with the radiologist seriously because the xray residents look at so fewpediatric xrays that they misread them all the time.
- 2098 17YO female presented by female intern. Patient is the one mentioned above who has returned
- from last week. During most of these rounds she was on the phone trying to get a psych consult.
- 2100 "She is very, very frustrated. Still in a lot of pain. Saying throwing up all the time. Night nurse
- said only once overnight so she may think she is but she is not." "She did admit to smoking
- 2102 marijuana and spice" "She wants to leave." "Psych is saying anxiety may be causing the vomiting2103 and headaches." Female intern
- 2104 "So the real recommendation is therapy. He recommended not starting an SSRI if she is non-
- 2105 compliant-setting ourselves up legally." Female intern.
- 2106 "My main goal is to try to talk to mom. Try to convince mom anxiety is a huge issue." F. intern.
- 2107 "She doesn't' feel like we are helping her." Male senior resident
- 2108 6YO male. "Bio mom is scheduled to come tomorrow. CYFD will be present the whole time"
- 2109 female intern.
- **2110** Group convened at 11 am.
- 2111 <u>Day 19</u>
- 2112 8:52 am conference room
- 2113 Female senior resident, female 3rd year medical student,2 male interns, male 3rd year medical
- 2114 student, female intern, and female attending. (7 total)
- 2115 Attending asked if any of them couldn't be a doctor what would they be?
- 2116 Female med student-chef
- 2117 Female senior resident-preschool art teacher
- 2118 Female intern- teacher or school nurse
- 2119 Female attending-baking or something where you work less (laughs)
- 2120 Male medical student-combat/para rescue

- 2121 Male intern- global public health officer
- 2122 Male inter-art history Phd "You can still do that" said another intern to which he responded "not
- with the loans I owe"
- 8 WO male presented by male intern "Began to question her who came from lactation and she
- said it was a doctor with and interpreter. I don't think it was lactation"
- 2126 "Does she think me and you?" male inter to female attending (laughs)
- 2127 "You are probably right. She had never met you before. I feel bad! We were a completely
- 2128 incompetent lactation consult!" Attending
- 2129 "If she lives in ABQ she can get her out that night." Female resident discharge as soon as the
- child's treatment is over
- 2131 "she is" male intern
- 2132 2 YO male presented by male intern
- 2133 "Mom was in the room too with one of his relatives. Dr. (blank) is concerned parents are giving
- 2134 him liquid and not writing it down. I explained to mom how important it is that we know all he is
- 2135 given. Male intern "reinforce strict I's and O's which I did" (laughs)
- 2136 10 YO male presented by male intern. This was just a quiet discussion of care plan
- 2137 14 YO female presented by female 3rd year medical student.
- 2138 "I just found this out-we ordered (medication) no one changed the bag" male intern
- 2139 "Have you ever filled out a patient safety report?" attending
- 2140 No one had
- 2141 "We should do it. Whenever a patient error happens we do a report so we can look at what went
- wrong. You make an electronic not and that is good but talking to the nurse is good. That's why
- 2143 we try to pull them in to rounds." Attending "luckily-she is fine."
- 2144 Pediatric surgeon came in "is [patient name] ever going home?" (laughs)
- 2145 "we hope" attending
- 2146 "Coordinate with us and we can see him at the same time-if he ever goes home" surgeon
- 2147 6YO male presented by male intern "Foster dad in the room didn't have questions."
- 2148 6 YO female presented by male intern "talked to [doctor?] in Omaha or Nebraska" to see about
- 2149 nutrition for patient. "Sorry, could have done that quicker" male intern in reference to his
- 2150 presentation style for that patient. The male medical student next to him kept rolling his eyes
- every time this inter would present.
- 2152 9 YO male "What is limiting discharge is diet as you all know." Male intern
- 2153 Nurse concerned about pulling PIC line because "he is such a hard stick" and will require weekly
- 2154 labs. Then there was a conversation about charting I's and O's (ins and outs). They decided to2155 pull the PIC
- 2156 "Nurse were concerned, then [dr's name] but apparently it was the parents' concern but when
- they went back they went back the parents were gone." Attending.
- 2158 "When I had left yesterday I got a page from the nurses that the parents wanted to talk to a doctor
- and I told them they would have to get you. Did you get a call?" male intern
- 2160 "no" attending (laughs)
- 2161 "Social work-CYFD determined he is not able to go back to Española. I guess grandparents are
- there to care for him..." male intern
- 2163 "check in with social work" attending

- 2164 12 YO male presented by male intern
- 2165 "hyper (medical term)" attending
- 2166 "no, hypo" female resident.
- 2167 "I don't know if it was from our notes or from outside but hypo would make more sense"
- attending
- 2169 "mom said he would like to be knocked out as much as possible "(laughs) male intern about MRI
- 2170 Nurse practitioner came in to whisper to the senior resident about a new kid in the emergency
- 2171 "He [doctor] knows she is here?" female senior resident
- 2172 "yes. And he is not impressed" NP
- 2173 15 YO male presented by female intern. "With 'GI kids' I don't know how strict I's and O's2174 need to be"
- 2175 "counts of voids is fine." Female resident
- 2176 "Touch base with nursing and make sure that is happening." Attending
- 2177 1 YO female presented by male intern. "sign out said they ran out of Similac again!" male intern2178 "again?!" attending
- 2179 They looked up the notes and kind of argued for a minute and then they realized that he was
- 2180 wrong and they were not out of similac again.
- 2181 "We can start it until mom meets with [Dr. name]." attending "Dr. [blank] expressed concern this
- 2182 baby would be best to go into foster care. " "Mom said she is thinking about going back to
- 2183 mexico." "Cases like this can be long and difficult...wouldn't say anything to mom but wouldn't
- be surprised one bit if she winds up in foster care. I don't' know if mom will be able to care forher" attending
- 2186 "She said something about hoping to see kids and that is why she wants to leave baby with her2187 neice and go back." Female intern.
- 2188 "Just to visit. Don't know how safely she can get there and back. Don't know her status" male2189 intern
- 2190 "Dad thinks she's abandoning him and none of the babies illness is true." Male intern.
- 2191 "If mom can do this safely remains to be seen" attending
- 2192 9 YO male presented by male intern
- 2193 "He ate an orange but did not eat a banana" male inter (laughs)
- 2194 "Tell him to keep eating bananas" senior resident (laughs).
- 2195 They talked about planning a meeting with the family to prepare for his discharge (he has been
- 2196 here 36 days). At the meeting they want the female attending who has had him most, interpreter,
- 2197 discharge planner, social worker-
- 2198 "we go?" male intern and the resident nodded yes.
- 2199 6 YO female presented by male third year medical student.
- 2200 Transferred from another hospital "Opio-naïve"
- 2201 "oral pain management means one step closer to going home" attending
- 2202 "I'm liking our 'schedule around the person' for labs" attending
- 2203 15 YO female presented by female 3rd year medical student. Patient transferred by outside
- hospital.
- 2205 "She says pain is worse and mom said it too, especially since we mentioned discharge" female
- 2206 med student "We think it hasn't worsened but mom thinks it has."

- 2207 "Mom won't like that" female med student about planning discharge
- "Only thing you didn't see yet was the lab results from the outside hospital and they were allfine" female intern
- 2210 "[child] seemed okay with going home. [child's] mom was like 'she's not better." Female med
- student (eyes got really wide)
- 2212 "She told me it hurts her stomach to stick out her tongue which is odd." Female intern
- 2213 "You haven't seen that?" (laugh) intern.
- 2214 "My toe hurts when I stick my tongue out." Female senior resident. (laughs)
- 2215 "sexual history?" attending
- 2216 "Yes. Extensive but she was adamant that she has not been active." Female resident
- 2217 "mom was not happy." Medical student
- 2218 "We are not gonna do ourselves a favor by kicking them out." Attending
- 2219 "Have to convince mom that she is comfortable." Female resident
- 2220 3 WO female presented by male 3rd year. Transferred from Santa Fe hospital.
- 2221 "Nothing overnight" male med student
- 2222 "none?! Zero?!" attending
- 2223 "none" male med student and female intern
- 2224 "night nurse had concern over social issues. That mom is young and seems immature. I told her2225 aunt and grandma are there all the time." Female intern
- 2226 "Mom has been completely appropriate! I have seen her do every feed. Yes, she is young but
- being young is not an issue." Attending with a tone of anger at the nurse.
- 2228 8 YO male present by female intern. "strict I's and O's" "Calorie counting should have been
- done. I will reiterate that to mom" "mom is once again thinking he is going home tonight (eyes
- roll) female intern (laughs)
- 2231 "Though they were going home since the night they got here." S. resident
- 2232 "and every day since "female intern.
- 2233 Ended at 10:32
- 2234 Carrie Tingley Patient meeting 11 am in 5th floor conference room
- 2235 Present: 3 female healthcare providers (HP), female specialist 2 female nurses,4 female
- administrators, 1 male therapist, 2 female therapists.
- 2237 6YO female Administrator began by describing the cultural status that they needed to establish
- for the girl such as language, religion and so on. There was a discussion about how to gather that
- information and then they realized that the nurses gather it during intake and put it in thedatabase.
- 2241 "If its in the database do we need to do it?" Admin
- 2242 "Is it something the nurse can report on a new admit?" admin
- HP said yes.
- 2244 "Number one factor is she has chronic illness" CM
- 2245 "Mom is chronic caregiver-wants to be intimately involved, has information of the disease
- 2246 process that I have no idea about-and she problem solves. Mom's pretty saavy but one piece she
- is not as saavy as she needs-don't know if needs-she thinks she knows TPN but that is what got
- her here." HP
- 2249 "You have to communicate clearly with mom" admin

- 2250 "I tried presenting it as mom's idea which seems to work." HP
- 2251 "When [dr. name] left he didn't refer anyone out." Female therapist
- 2252 "Mom wants to transition to an outpatient plan asap" HP
- 2253 "Not a 'guillan barrett' for sure" HP
- 2254 "I didn't make her do anything-why would you fabricate that?" Therapist (laughs) " She is totally

behavioral, totally over hospitalized, just wants to lay there like a blob. Her behavior is not

- 2256 compatible with PT and not do anything and she bit her mom" Therapist
- 2257 "Biting?!" specialist
- "gets so upset. I'm borderline not going to see her." Therapist "I feel sorry for anyone having to
 work with her. She tried to kick me! She just wants to be in bed" so leave her there. The woman
 from child life agreed with the Therapist.
- 2261 "Mom is just numb to it." Therapist
- 2262 "Would it make a difference if mom wasn't there?" HP
- 2263 "no. Mom just wants ducks in a row to go home." Admin.
- "I asked her about her legs and she screamed 'It hurts!" Mocking tone by specialist "she's kicking him!"
- 2266 "Motivated by hurting people." Admin (laughs)
- 2267 "I'm done with her if she's getting so upset she's barfing up her food and meds." therapist
- 2268 "What is she doing in school?" specialist
- 2269 "Just has a 504 because family can't always get her to school on time but that is it." HP
- 2270 "I think she does have sensory pain and fear and 'hospitalitis (laughs) on top of it" Therapist
- 2271 "Mom didn't want to come so she did do better without mom there. Do think she is one of those
- who would do good on a behavioral plan if she was staying for a while but it takes a lot for that to
- happen." Therapist
- 2274 "She's poor all the way around" Therapist
- 2275 "Mom hasn't given anyone a chance." therapist
- 2276 "Mom herself needs to not be so self centered. She needs to understand that her daughter is on a
- 2277 unit and not princess. Mom would have to be on a behavioral plan if she was staying and doesn't
- 2278 want to do that or take responsibility for herself." (laughs) therapist
- 2279 "They have previous experience with a family member with disability so they think they can do
- everything. Okay! (mocking) She wants to build her own bath chair" (huge laughter from a couple of people) therapist
- 2282 "Didn't get a good feel from mom" therapist
- 2283 "They need us. So sad" admin.
- **2284** 9 YO male
- 2285 "Mom is okay. Seeing minor improvement in him but she is still thinking about transferring to
- 2286 CHOP but insurance will be hard to sell." HP
- **2287** Female Doc came in at 11:25 am.
- 2288 "Mom has to leave for a week" HP
- 2289 "Nothing new. Same ole same ole." therapist
- 2290 "mom is not doing well" specialist. "went to court and shared custody so that is good. Her
- daughter went to Hawaii with relatives and she is having a hard time with that. Took her to coffee
- in the morning and she just sobbed." specialist

2293 "She's here a lot!" admin 2294 "This is her life! " specialist. "She was the CFO of a computer company and then she did her 2295 master's in special education." 2296 3 YO male 2297 "Interesting kiddo" HP "native American kid-one of two children left in a bathtub and on 2298 drowned and the parents are in prison. Living with Mom's cousin but she doesn't really want 2299 him. He yells and screams at the mom and dad if they attend to their own kids." HP (sounds of 2300 disapproval) 2301 "ooooh." Admin 2302 "Grandma had him but everytime the mom would see them his eyes weren't working right.." She 2303 told a story that was hard to follow but someone (I think foster mom's) husband worked for the 2304 police so they reported grandma to CYFD and then placed the child with this cousin and then 2305 talked about old abuse related head injury child has. 2306 2307 "Clearly has emotional issues. Foster told me all of this stuff in front of hime. I don't know how 2308 much he understands but when I asked him to say his ABC's he started to cry" HP 2309 "oooh." specialist 2310 "Her husband wants the kid more than she does." "I broached the subject of the preschool for the 2311 blind that is in ABQ to make the case for him staying here with her family. She seemed willing to 2312 look at that and keep it in mind to keep him in ABQ" HP 2313 "He is here for vision and to establish a safe plan. He is from Twin Lakes near Gallup" HP "abuse 2314 happened in Bio home." 2315 "Is he FAS kid? Stubby fingers?" Admin (fetal alcohol syndrome) 2316 "no" HP 2317 "Is there any other siblings?" HP 2318 "Just the one that died" HP "He called her momma" [foster mom that doesn't want him] 2319 "But she doesn't want him" specialist 2320 "She might just be looking at long term" female therapist 2321 "Medical foster placement?" admin 2322 "She was attendive" HP 2323 "Time will tell" Admin 2324 "Tribal social services told them 'take him home for a month or two and then, if you still don't 2325 want him, we'll take him to another placement." HP 2326 Meeting convened at 12 pm. 2327 "They've got a failure to thrive they want to talk to you about" HP to female therapist 2328 Day 20 2329 8:28 Office of the nurse case manager for "3 south" which is an adult orthopedic inpatient unit. 2330 I explained to the CM a bit about what I am studying. She was talking to an attending physician 2331 and said "you can't cure stupid." I thought she might be talking about staff but I think it was 2332 about a patient who will be described a few times later. 2333 We went into a conference room and were joined by a Female Occupational Therapist (OT), a 2334 female physical therapist (PT) and an OT student who was also female. Followed by a female 2335 doctor a male doctor, and another nurse case manager female.

"Got some 'Nuero" OT 2336 2337 "One guy was 180 degrees in his bed...not the sharpest tool in the shed" CM 2338 "Did you go to the memorial" female doctor 2339 "Yes, and it was completely [former employee who passed]" CM 2340 1st patient: Male "Wife works here" female doc 2341 "oh, her!? Wow" OT 2342 2nd patient: nothing 2343 3rd patient: "She is immediately going. Not soon enough. They just changed her psych meds. 2344 Any amount of time is too long" male doctor 2345 4th patient: "He originally was thought to be in a car accident but he told the neurologist he was 2346 attached by a mountain lion." Female doc (laughs from male doc and male charge nurse) 2347 "Lion drove a car into him" CM 2348 5th patient: "He doesn't matter from our perspective." Male doc. 2349 "nothing going on in 4s." male doc 2350 "good" female doc but it was actually a joke and it had been busy and understaffed for a few 2351 days. 2352 "Pretty rough, ugly days." Male doc and female CM 2353 "No one died though!" other female CM 2354 "Get em to NICU before they die!" male doc (laughs) 2355 Then they talked about how painful shoulder surgeries are: "its horrendous" male doc. 2356 They also talked about "grey medicine" CM and male doc which sounds like geriatric care 2357 Patient 6-9 nothing 2358 Patient 10: "This guy this morning was 180 degrees in bed with leg through the side rails! " CM 2359 "You missed this but he came in and snapped into DT's and had to go down to the MICU" female 2360 doc 2361 "He's...." CM 2362 "Moved him back to the floor." (laughs) female doc 2363 "noooo funding" CM 2364 "could he go to roswell?" Female doc (city in Southern NM) 2365 "Could" CM 2366 "TBI?" female PT 2367 "Whats a TBI?" male doc 2368 "Traumatic Brain Injury" PT (OT laughed and they looked at each other in horror that the doc 2369 didn't know what TBI means) 2370 Patient 11: 2371 "He is funded" CM 2372 Patient 12: "Is he funded? Can get to rehab?" Female Doc 2373 "he is self pay" CM 2374 "He takes his brace off then gets up" male doctor 2375 "Oh, God" CM 2376 "Not good" male doc 2377 Patient 13: Discharge "great news" male doc 2378 "I can gt one month of oxygen for her from our indigent program but that is it? CM

- "funded" female doc 2379
- 2380 "BCBS UNM employee who is 5'4" and 300 lbs. Has husband and 3 kids at home who can't help
- 2381 her "CM "I'll get her somewhere"
- Patient 14: "She's 25 and won't walk?!" 2382
- "She's a dwarf" "Wheelchair bound" several people spoke at the same time. 2383
- 2384 "Where does she live?" Female doc
- 2385 "Home with grandma grandpa, brother, sister-in law and 5 kids" CM
- "Just watched Cheaper by the Dozen" female doc (laugh) 2386
- "I think grandma gets paid to care for her. She is on the Disabled and Elderly waiver." CM "Turf 2387 her to social work." 2388
- 2389 Patient 14: "VA funding" CM
- 2390
- This meeting was over and the group changed at 9 am for a recertification meeting for the unit
- 2391 attended by : female purchasing agent, female quality manager, female spine nurse, female case
- 2392 manager (CM), female doctor, male charge nurse, male doctor and male unit director.
- 2393
- 2394 Female doc told the group that her niece was coming in with a cat bite and she didn't want her to
- 2395 go to the pediatric ER so she was going to look at it. Had put her on an antibiotic "Stupid- no
- 2396 offense but some stupid nurse practitioner put her on some shit antibiotic. I changed it"
- 2397 The male doctor started to ask me about my study, if my thesis was written to which the female
- 2398 doc said "look at you with your smart questions!" The male doc seemed to get embarrassed and
- 2399 looked away and wouldn't make eye contact the rest of the time.
- 2400 This turned out to be a process meeting and outside of the scope of what I am looking at so I am
- 2401 not going to proceed but I have notes in case it becomes relevant later.