THE DUAL PURPOSES OF THE DUAL PROCESS MODEL OF SOCIAL COGNITION IN CRITICAL CARE COMMUNICATION: IDENTIFYING CLINICIAN AND FAMILY DIFFERENCES IN EXPECTATION DEVELOPMENT, AND PREDICTING INTERVENTION SUCCESS

By

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To My Dad, for expecting so much – To My Mom, for expecting so little

And

To my children, who can expect me home more often once this is complete

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CHAPTER I

INTRODUCTION

Purpose

The purpose of this work is two-fold: first, to characterize communication between clinicians and families of patients in critical care; and second, to establish a conceptual framework to inform the design of family-centered critical care communication interventions. A case study of the Vanderbilt Regional Burn Center was undertaken with investigation encompassing its staff, operations, communication, inpatients, and visitors, in collaboration with The SEE Project research and intervention development team from the Vanderbilt University Center for Biomedical Ethics and Society.

Significance of the Study

The significance of this study is multifaceted. First, it aims to improve communication by preventing conflict between clinicians and families of patients in critical care. The most proximal outcomes of improving communication for families are greater confidence in decision making, and increased satisfaction with patient care; and for clinicians, decreased caregiver strain and improved decision making. Medial outcomes affecting the patient include: better-informed care resulting from improved joint decision-making, quicker recovery, increased social support, and improved adherence at follow-up. Distal outcomes, affecting the hospital and broader healthcare structure, include increased accountability of healthcare professionals, decreased cost of care, and reduced risk of litigation.

Second, this study proposes a social cognitive explanatory model for (a) interpreting communication differences between clinicians and family members; (b) analyzing communication differences between distinct clinician groups (physicians vs. nurses); (c) identifying necessary and

sufficient components of successful communication interventions; (d) designing "smart" communication interventions that are supported psychosocial-neurocognitive research, and (e) predicting the value of a proposed communication interventions based on the intricacies of human cognition and social behavior, within a neuroeconomic framework.

Thirdly, a social cognitive approach to intervention design is innovative in the context of healthcare communication-as-usual. The architecture of an evidence-driven approach to intervention design founded on a neuroeconomic understanding of interpersonal communication revolutionizes intervention research, making it more efficient, cost-effective, and predictably successful.

Finally, an in vivo social-cognitive exploration of the problem-solving process allows for efficient implementation of a systems-integration design, and for future site-specific intervention designs to reflect a growing knowledge of critical care communication. In essence, the process shortens the evidence feedback loop such that ineffective or inefficient intervention components can be isolated and rejected, and adjustments to improve the intervention can be made within the context of the study design.

Background: The SEE Project

Family members of patients in critical care are often faced with the distressing news that the patient's condition is worse than they anticipated, that they will not return to former levels of functioning, or that chances for survival are minimal. Under such circumstances family members may be expected to make decisions about procedures with an unfavorable risk-benefit ratio (Sweeney, 2008), about which type of continued care is appropriate (aggressive vs. palliative), or about the withholding or withdrawal of life-supporting interventions (Curtis, Patrick, Shannon, Treece, Engelberg, & Rubenfeld, 2001). Ideally, such decisions are guided by recommendations of the physician, based on expertise gained from both medical literature and their personal experiences in similar situations. Often, however, family members disagree with physician recommendations, resulting in delays in treatment, withdrawal of treatment,

transfer to another facility, earlier-than-recommended disposition, and poor adherence with follow-up care—all associated with poorer outcomes for the patient.

A multidisciplinary task force of experts in critical care practice from the American College of Critical Care Medicine and the Society of Critical Care Medicine was convened in 2004 to establish clinical practice guidelines to support patients and families in intensive care units. The committee reviewed over 300 articles related to healthcare decision making, family coping, clinician stress, cultural and spiritual support, family visitation and presence, family environment, and palliative care. The committee endorsed shared decision making, early and repeated care conferencing, honoring culturally appropriate requests for truth-telling and informed refusal, family presence at rounds and at resuscitation, open and flexible visitation, spiritual care, bereavement support, and staff training and education as ways to reduce family stress and improve consistency in communication (Davidson, et al., 2007).

At Vanderbilt University Medical Center, conflicts between physicians and family members warrant response from the Ethics Team from the Center for Biomedical Ethics and Society. The intervention initiated by the Ethics Team is termed a family conference or *crisis meeting*, and is an effort to mediate between physicians and family members in order to establish the appropriate course of care. Because the crisis meeting occurs post-conflict, both family members and members of the medical team may be experiencing intense emotions, which could impair judgment at a time when reasoned decision-making is imperative. Expert guidelines for family conferences encourage communication about patient and family treatment preferences, clinician recommendations, and options for end-of-life care. Advanced planning by clinicians of family conferences is recommended to determine what information should be shared, where the meeting should occur, and in conjunction with the family, who should be present during the meeting (Curtis, Patrick, Shannon, Treece, Engelberg, & Rubenfeld, 2001).

One approach to improving communication between physicians and family members involves helping to formulate appropriate expectations for family members early in the care process, including: expectations about survival, expectations about frequency and source of communication regarding the patient's condition, expectations about milestones that influence patient outcomes (i.e. surgeries, changes

in ventilation), expectations about decision making, and expectations about long term care, potential outcomes, rehabilitation, recovery, and disposition.

Family members of patients admitted to intensive care units often face a series of unexpected events. These unexpected events frequently preempt distress, confusion, and at times distrust of the medical team and lack of confidence in the patient's quality of care. Confusion, distrust, and lack of confidence may trigger family members to challenge medical recommendations, resulting in delays of necessary treatment, withdrawal of unnecessary or non-beneficial treatment, or disposition. Attempts to remediate such problems constitute family-centered care.

Family-centered care is an extension of patient-centered care, an approach to medical care that aims at the development of mutually beneficial relationships between patients and clinicians. Family-centered care highlights the importance of the role family members play in promoting the patient's well-being. In critical and intensive care, when the patient is typically unable to respond, the family is particularly crucial; first, in delivering medical history that may inform treatment decisions when the patient is unable to do so, and secondly, in acting as surrogates to make medical decisions on the patient's behalf. Family-centered care is grounded in the key concepts of respect and dignity, information sharing, participation, and collaboration, and is considered central to the ethical delivery and planning of contemporary health care. While the vision of family-centered care is already widely embraced, continued efforts are required to improve its implementation in practice. The aim of this project is to develop recommendations for interventions that incorporate evidence-based family-centered critical care delivery, while targeting problem areas that are specific to the VUMC burn unit as defined by observational data and family and clinician reports.

The Research Problem

Objectives

The primary objectives of this study are 1) to identify the causes of clinician-family communication conflicts in critical care, including differences in clinician-family expectations, decision-making, and social cognition; 2) to propose an intervention strategy to improve critical care communication, including identification of key roles and processes essential to an effective intervention, and 3) to evaluate the research process in order to make recommendations for intervention research.

Most commonly, family dissatisfaction arises not from the quality of care the patient receives, but from issues of communication between clinicians or hospital staff and family members. To improve critical care communication between physicians and families, it is first necessary to characterize the nature of the communication problems that exist, the structural/environmental boundaries in which that communication occurs, and the targets (key roles) of a proposed communication intervention.

With a multi-factorial understanding of environment- and situation-specific communication in the unit in mind, it becomes possible to conceptualize an intervention approach that will integrate key players and target key problems in communication that have been identified. Conceptualization of an appropriate communication intervention relies on identifying a theoretical framework by which critical care communication, and site-specific communication problems, may be addressed.

By establishing a unified theory with the dual purpose of predicting communication failures, by characterizing communication problems, and predicting communication success, by integrating evidence-based intervention components into a site-specific adaptive design, it is possible to preempt and prevent family communication crises in critical care settings.

Characterizing the communication

General observations will be evaluated to identify a general rhythm of the day—the purpose of this measure is to identify occasions which generally preempt problematic communication, structural

boundaries of communication, and opportunities for implementation of a communication intervention. In addition, themes identified from general observations will be used to structure focused observations.

Focused observations will be evaluated to identify problematic communication events identified by the observers, including conflicts in communication and anatomy of a communication crisis (events that result in the need for a crisis meeting/ethics intervention); and to better understand communication protocol, including how physicians reach consensus in patient assessment and care plan, how and what clinicians communicate to family members, how families develop expectations about patient outcomes, and how clinician and family expectations influence decision-making.

Clinician semi-structured interviews will be evaluated to identify how clinicians construct expectations about the patient, clinician goals/plans for communication with families, and clinician perspectives of communication obstacles. Family semi-structured interviews will be evaluated to identify family satisfaction with clinician communication about expectations for the patient, family perception of obstacles to communication, family perceptions of helpful communication.

Conceptualizing the intervention

Conceptualizing an intervention approach that is both broad enough to address a myriad of factors relating to communication, yet specific enough to meet the needs of a particular unit, requires a multifactorial approach. The investigation will identify what information and resources are required to develop a family centered intervention to address the needs of a specific hospital unit, what obstacles to implementing a successful family centered intervention exist, and how success of a family centered intervention can be assessed.

First, a thematic analysis of literature regarding family-centered communication interventions, with an emphasis on critical care, will identify types and components of interventions that have demonstrated a reasonable degree of success, as well as measures which are likely to be targeted by such interventions or intervention components. Second, an evaluation of the research protocol, steps toward intervention design, and obstacles to intervention design and implementation will provide a dimensional

understanding of how underlying theoretical approaches impact the utility of proposed interventions, as well as the efficacy and efficiency of the intervention design process.

Integrating problems and problem-solving

An explanatory model of physician and family communication will provide insights to understanding current communication and identifying communication problems, allowing for a problem-focused approach in design of the communication intervention. A dual-process perspective of social-cognitive decision making will serve as a scaffold for interpreting physician and family communication differences within a neuroeconomic framework, and guiding design of an intervention that is widely generalizable to other critical care settings, and malleable to meet the specific needs of individual critical care units. Concepts from systems integration theory will provide a foundation in formulating the general architecture of the intervention, as well as its delivery and sustained implementation.

Definitions

BICU—Burn Intensive Care Unit; provides emergency care for burn patients in critical condition

Crisis meeting—intervention by the ethics team in response to clinician-family communication problems

Cultural transmission—a process by which people learn and transmit cultural information

Dual process model—a theory about decision making developed by social and cognitive psychologists

Enculturation—a process by which cultural expectations, values, beliefs are acquired

Family-centered—health care practices that incorporate the family of the patient

Family satisfaction—a measure of family-centered care, and a marker of desired treatment outcomes

Grounded theory—a social science method of inquiry in which data informs hypothesis generation

Neuroeconomics—a biological understanding of cognition, especially in regard to decision making

Rhythm of the day—integrated system understanding of roles, functions, and routines in the BICU

Rolemaking—a process by which role expectations are acquired through interactions with others

Social cognition—processing information about other people, especially from nonverbal communication

Step down—unit for burn patients in non-critical phases of recovery and rehabilitation

Systems integration theory—a interdisciplinary method of engineering systematic change

Theory of mind—the ability to distinguish the mental states of self and others

VRBC—Vanderbilt Regional Burn Center; includes the Burn Intensive Care Unit and the Stepdown Unit

Delimitations, Limitations, and Assumptions

Delimitations

The following elements were directly controlled by the investigator for the purpose of this study:

- Direct observation of unit behaviors and communication and access to clinical observation transcripts.
- 2. Access to clinician and family interview transcripts.
- 3. Independent assessment of all data.
- 4. Independent review of literature surrounding family-centered care, communication interventions, social cognition in decision making, and neuroeconomic theory.
- 5. Novel application of a dual process model of social cognition in the evaluation of healthcare communication.
- 6. Demonstration of relevance of neuroeconomic perspective in critical-care decision-making.

Limitations

The following elements were not controlled by the investigator:

1. All data was collected for the SEE Project under the direction of primary investigator Dr. Joseph Fanning by members of the SEE project research team for a feasibility study in family centered intervention research and design, thus data collection was limited in scope and sample size was sufficient to this end. The study was not statistically powered to draw empirical conclusions.

- 2. All data collection instruments were designed by members of the SEE Project research team for investigation within the domains of applied medical/healthcare ethics and human factors/system integration, with the specific aims of identifying communication obstacles. Since the data collection instrumentation was not specifically designed for analysis using a dual-process model of social cognition, construct validity has not been established and external validity is limited.
- Interviews and observations were conducted by Dr. Joseph Fanning, Dr. Anne Miller, Dr. Larry Churchill, Dr. David Schenk, Dr. Paula DeWitt, Tinsley Weber, Christina Farkas, John Burnam, and Susan Piras.
- 4. The time frame of data collection for the feasibility study and intervention design research was inconsistent with the completion of the thesis study at hand, thus variance between current reported values and future reported values from feasibility study data is expected.

Assumptions

This project assumes the following regarding data collection and theoretical perspectives:

- The accuracy and expertise of ethicist reports from Vanderbilt's Center for Biomedical Ethics and Society regarding the characterization of crisis communication and the salience of precipitating events.
- The accuracy and expertise of researchers from the multidisciplinary intervention research team
 regarding the characterization of observations within the burn unit and compliance with all
 requirements for conducting research with human research subjects.

CHAPTER II

METHODS

General observations

Instrumentation

Investigators observed and transcribed information detailing all persons and activities observed within the burn unit throughout the day. Observations were transcribed by multiple investigators working individually or in pairs. Paired observations were compiled to represent a complete data set without replication. Transcripts were input into Excel software for coding and analysis. Investigators were allowed to informally ask questions of clinicians and staff as needed to clarify ambiguous situations, and these questions and responses were transcribed. Investigators did not interact with patients, visitors, or family members and did not transcribe personal identifying information such as names, date/time of admission, patient ID, date of birth, employer, or other identifying descriptors.

Subjects

For the purpose of this analysis, subjects were categorized as clinicians, family, or staff.

Clinicians included all health care providers within the unit, including the following roles: attending physicians, fellows, residents, surgeons, nurse practioners, charge nurses, bedside nurses, physical therapists, occupational therapists, speech therapists, social workers, and other members of the Burn Team who provide direct patient care. Staff includes non-clinical roles such as administrative assistants, receptionists, janitorial staff, and those whose roles were unknown but who may have interaction with patients or family members.

Family is a broad designation including the patient, spouse, non-married significant others, and any other family member or non-related friend or visitor who participated in decision-making for the

patient, would be involved in caregiving for the patient following disposition, or who significantly influenced family dynamics (examples: patient was brought in by neighbor and has no other family—neighbor has been involved in previous care and plans to assist with recovery care; grandparent has been raising child in parent's absence, etc.), whether present or absent but referred to in communication, (e.g., the patient's wife is not available to provide consent, or family member with power of attorney has not been contacted). Visitors included any person who visited the patient, whether related or not, who did not participate in decision making, plans for ongoing care, or significantly affect family dynamics (and thus were not primary targets of communication).

Procedures

Observation of the persons and activity within the VRBC was IRB approved, and investigators received permission from the VRBC board of directors and attending physicians before proceeding. All clinicians and staff were informed of the investigators presence and purpose prior to the investigation.

Activities observed and transcribed included activities of daily care such as patient admissions procedures, examinations, labs ordered, administration of medications, and other routine administrative and clinical activities; medical procedures such as resuscitation, surgeries, hydrotherapy, and other emergency or planned non-routine procedures; and communication, including any speech or conversation by clinicians, family members, visitors, or staff. Some examples of communication include clinician speech during rounds, patient assessments, procedures, updates, and delegating tasks; family conversations about decision making or questions to doctors about the patient; conversations between clinicians and family regarding patient medical history, current condition, or care decisions; conversations (including phone calls) between staff and family or clinicians regarding contact information, parties responsible for decision making, financial obligations, or documentation of patient's wishes (i.e. DNR, living will); and any other communication deemed relevant by observers.

Analysis

Observations were coded by a team including the observing investigators and naïve investigators (who were unfamiliar with the VRBC environment and activities) using a grounded theory approach.

Coded data was assessed for relative frequencies and subjected to thematic analysis to identify themes related to development of expectations. Inter-coder reliability sufficient for statistical analysis was not established, due to the non-specific and varied nature of the information transcribed.

Focused observations

Instrumentation

Themes relevant physician and family expectations were identified from general observations, and served as a guideline for focused observations. Focused observations were limited to communication, including speech and nonverbal communication behaviors (pointing, covering face with hands, waving someone away, gesturing for someone to approach, etc.) Other activity (daily tasks, medical procedures, etc.) was excluded, except when necessary as a context for understanding the context of the communication (e.g., speech = attending told nurse to get the family; context = because the patient's condition had suddenly worsened, and he wasn't expected to survive).

Focused observations were further limited by role; only communication by clinicians, family (patient, spouse, family members, other decision makers), and investigators was transcribed.

Communication by staff and visitors was excluded, except in cases where it was determined to be relevant to understand the context of the communication or family dynamics (e.g., the patient's neighbor who called 911 to report the fire—but has no decision-making or caregiving responsibility—claims the spouse, who was also primary decision maker, had not been in contact with the patient for several years; the staff administrator explains that the spouse was contacted based on previous hospital admission information and requests the neighbor to provide contact information for current significant other or other family member).

Transcriptions were input into Research Electronic Data Capture (REDCap) software to maintain the security of potentially identifying patient data, and original written transcripts were destroyed. Each family was assigned a Family ID linking them to the patient using encrypted information. Identifying information about the family was not recorded; family members were identified by their relationship to the patient only (mother, father, sister, brother, spouse, significant other, etc.) Identifying information about the family was encrypted using elements of the patient's room number, date of admission, sex (male or female), and initials. Obtaining identifying information about the patient was necessary to maintain continuity, as patients may be moved from one room to another several times over the course of their stay.

Subjects

Subjects of study included clinicians and consenting family members of patients who remained in the unit three days or longer. Physician report and observer interpretation using physician-provided guidelines were used to identify patients who were likely to survive and remain within the burn unit for at least three days; patients who were deceased, transferred to another unit, or dispositioned before three days were excluded from the study.

Family members of patients who met inclusion criteria were identified and informed consent was obtained for observation by investigators of patient and family. Patients whose family members were either not present, or declined to consent to observation, were excluded from the study. Families were requested to opt in to be contacted for a family satisfaction survey. Families who did not opt in were included in observation data, but were excluded from family satisfaction survey data.

Procedures

Investigators attended physician rounds of the BICU at 8:00 a.m. and 4:00 p.m. daily, and interdisciplinary rounds of the BICU and Stepdown unit at 9:00 a.m. daily. Communication was observed and recorded in relation to eligible, consented patients only. Clinician and Family

communication occurring within the VRBC was linked to the patient's Family ID and logged sequentially over the course of the patient's stay. Families who opted to provide survey data were contacted in person or via phone by an investigator and family satisfaction surveys were administered.

Analysis

Focused observations were coded and subjected to thematic analysis aimed at characterizing the content of communication by clinicians and family members related to expectations. Communication events included planned communication such as rounds, meetings, or family conferences; communication that functioned to build expectations, including prognosis, discussions of future course of care, orders for diagnostic tests, scheduling of surgeries and other procedures, and plans for disposition; and adverse communication events—a term used to describe any communication that appeared problematic, including misunderstanding of information presented, incorrect or inconsistent information provided, disagreements, confusion, intentional deception, or any event preempting a *crisis meeting* intervention by the ethics team. Units of communication (questions, statements, conversations, etc.) were coded to assess relative frequencies of different types of communication that influence expectations. Themes identified from focused observations were used to develop family semi-structured interviews.

Family interviews

Subjects

Families of patients who had been in the BICU for one week or longer were recruited to participate in a semi-structured interview regarding their experience in the BICU and communication with clinicians. Twenty families consented and were interviewed.

Procedures

Investigators interviewed family members individual or in pairs (two members from same family were interviewed together) using a series of open ended questions about their experiences with clinicians in the burn unit, with a particular emphasis on communication and barriers to communication. Interviews lasted approximately 40 minutes.

Investigators asked families a list of prepared questions about their first conversations with a clinician about what to expect over the course of the hospital stay, what kinds of information they found helpful, and what, if any, communication obstacles they encountered. Investigators responded to family speech in one of six ways: by rephrasing family responses and asking them to affirm their interpretation was correct (e.g. "It sounds like you're saying *[rephrased family response]*... is that right?"), by indicating that they understood the family's response or position (e.g., "Yes, I can see why you would think that"), by acknowledging the validity of their observations or opinions (e.g., "That's a really good point you bring up about how it was not what he said, but how he said it, that was so upsetting), by expressing sympathy (e.g., "That must have been very difficult to hear"), by asking the family member to elaborate (e.g., "Can you tell me more about that?"), or by asking specific questions to clarify the family member's response (e.g., "So when the nurse said he couldn't answer your question, did he explain why? Was it because he didn't know the answer, or did he not have the authority to give you that information?)

Instrumentation

The following is a sampling of questions asked in the semi-structured interview format.

Questions were omitted if the family member addressed the topic prior to questioning. Additional impromptu questions were asked in relation to the content of individual family responses.

Family Semi-Structured Interview

Initial communication

- Do you remember who on the healthcare team first talked with you about what to expect during this hospital stay?
- 2. When was that first conversation? How long was it before someone came to talk to you about the patient?
- 3. Do you remember where the conversation took place?
- 4. (If the physician was not the first to talk to them...) How long before the physician came to talk to you?

Helpful communication

- 5. What kinds of information did they give you that were especially helpful?
- 6. Was there any specific person—a doctor or nurse or anyone—who was very good about providing the information you needed?

Problems in communication

- 7. Did you have any problems getting the information you needed?
- 8. What, if any, obstacles did you face in terms of communication? Or, what kinds of things prevented you from getting the information you needed?

Table 1. Family Semi-Structured Interview Questions (Joe Fanning et al. for SEE Project 2012-13)

Analysis

Family responses were analyzed to identify the quality and content of the first communication they received from a clinician regarding the patient's condition, examples of clinician communication that were helpful, and examples of clinician communication that were problematic.

Clinician interviews

Subjects

Investigators interviewed ten BICU clinicians: five attending physicians and five nurses: two bedside nurses and three charge nurses (two of whom also worked as bedside nurses).

Procedures

Investigators conducted semi-structured interviews with clinicians concerning communication with families and expectations. Questions were asked regarding the timing, content, and goals of the first communication event with family members in order to establish (or share) expectations; incorporation of families into rounds and communication with absent families; information and strategies used by the physician to construct expectations for themselves about patient prognosis and course of care; managing surprises, uncertainty, and change in expectations over time; methods of gauging patient progress; and disagreements, or breakdowns in communication, with family. Clinician interviews lasted for approximately 80 minutes.

Instrumentation

The following is a sampling of questions investigators asked clinicians in the semi-structured interview format. Questions were omitted if the topic was sufficiently addressed in previous responses. Additional questions were asked to encourage physicians to elaborate on specific topics referenced in previous responses. Interviews were audio-recorded and later transcribed.

Clinician Semi-Structured Interview

Initial communication

- 1. We're trying to understand more about the initial communication with families about what to expect. Who does that first conversation with them?
- 2. When does the initial conversation usually occur?

Initial communication (cont.)

- 3. What is information is included in the initial conversation?
- 4. Do most physicians have a similar agenda for that first conversation?

Family incorporation

- 5. If the family is not available, does someone try to contact them?
- 6. What has been your experience with including families in rounds?

Constructing expectations about the patient

- 7. What are factors that shape your expectations for patients and future course of care?
- 8. How do you think about developing those initial expectations?
- 9. How do you handle suprises, or events that change your expectations later on?
- 10. Do you plan ahead of time for factors that might change your expectations?
- 11. When you first walk into a patient's room, what things do you look for to help you construct expectations about the patient?

Communicating expectations to the family

- 12. Do you talk to patients about things that could change your expectations about the patient's progress or course of care?
- 13. Does it help to provide milestones for families?
- 14. What do you think is the most helpful information to give families?
- 15. What kinds of things result in disagreements with families, or breakdowns in communication?

Table 2. Clinician semi-structured interview questions (Joe Fanning et al. for SEE Project 2012-13)

Analysis

Clinician interviews were subjected to thematic analysis and themes were identified related to problems in communication. Clinician interviews were evaluated in the context of the dual-process

theory of social-cognitive decision-making (Satpute & Lieberman, 2006). Physician responses to questions about constructing expectations were categorized as indicators of either C-style (*reflective*) or X-style (*reflexive*) cognitive processes. Trends and relative frequencies were assessed.

Dual Process Model of Social Cognition			
Refle <u>x</u> ive (X-style)	Refle <u>c</u> tive (C-style)		
Automatic coding	Inferential goals		
• Traits	 Situational constraints 		
Evaluation of behaviors	• Prior knowledge→		
Implicit associations	Altering implicit inferences		
• Fluid	• Symbolic		
• Contextual	 Propositional 		
Hypothesis-confirming automatic	Controlled corrections of automatic		
attributions	attributions		
Table 3. Dual Process Model of Social Cognition (content adapted from Satpute & Lieberman, 2006).			

Clinician and family behaviors identified from general and focused observations were categorized as either C-system or X-system processes for the purpose of coding. Clinician behaviors categorized as X-system included making generalizations or stereotyping, interacting with other clinicians within the cultural hierarchy, and social (non-clinical) interactions with patients or families that would include aspects such as perspective taking or empathizing. Clinician behaviors categorized as C-system included medical activities such as diagnosing, prognosticating, providing routine care such as patient examinations, following rules or protocols, and teaching residents (in rounds). Family behaviors characterized as X-system included interactions with the patient and family members, conforming to role

expectations, evaluating clinician responses to patients, and confirming hypothesis—a process by which current experiences are disregarded in favor of maintaining already-held beliefs, such as when patients and families perceive doctors as heroic, all knowing, or kind based on media representations even though the doctors they meet do not portray these qualities.

	X-SYSTEM	C-SYSTEM		
Clinicians	 Making generalizations (stereotypes) about patients Team dynamics Empathizing Perspective taking 	 Diagnosing Prognosticating Routine care Following protocols Teaching Rule-following 		
Families	 Identifying patient needs Operating within family dynamics Conforming to role expectations Evaluating clinician response to patients Confirming hypotheses (e.g., maintaining beliefs based on media representations of physicians in spite of contradictory experience) 	Excusing/justifying clinician communication obstacles Busy schedule Lots of patients Under pressure Rational decision making		
Table 4. Dual system categorization of clinician and family behaviors				

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CHAPTER III

LITERATURE REVIEW & THEORETICAL PERSPECTIVES

Three primary bodies of work were consulted in this study: literature on family centered care, systems integration, and social cognition. In family centered care, specific topics of focus included critical care and communication-based training interventions. Systems integration theory was consulted as a basis for intervention design and implementation, as well as program evaluation. In social cognition, specific areas of concentration included cultural transmission, decision making, and expectations.

Family-Centered Health Care

Introduction and theoretical perspectives

Conceptions of family-centered care have been in practice since the 1980s, and were spurred along by the Education for All Handicapped Children Amendments of 1986 (Lawlor & Mattingly, 1998). Family-centered care is an extension of patient-centered care, an approach to medical care that aims at the development of mutually beneficial relationships between patients and clinicians. Family-centered care highlights the importance of the role family members play in promoting the patient's well-being. While pediatric care has been the primary domain of family-centeredness, critical care represents a special case in which family-centered care is essential in the treatment of adult patients. In critical and intensive care, when the patient is typically unable to respond, the family is particularly crucial; first, in delivering medical history that may inform treatment decisions when the patient is unable to do so, and secondly, in acting as surrogates to make medical decisions on the patient's behalf.

In family-centered critical care, care delivery is organized around the family rather than the patient. Three primary needs of families of patients in critical care have been identified as information, reassurance and support, and the ability to be near the patient (Henneman & Cardin, 2002). From a

biopsychosocial perspective, family members are important resources in the patient recovery process (Atkins, Colville, & John, 2012). In this context, barriers to communication with the family could impair patient outcomes. Miscommunication between family members and members of the health care team can be seen as a cumulative result of a number of psychological and social factors, language and educational disparity, differences in goals and priorities, and issues of convenience, practicality, accountability, and empowerment.

Expectation management is one method of addressing conflicts in communication occurring between family members of critical care patients and clinicians. An underlying assumption of is that family members of patients admitted to intensive care units often face a series of unexpected events, and that these unexpected events frequently preempt distress, confusion, and at times distrust of the medical team and lack of confidence in the patient's quality of care. Confusion, distrust, and lack of confidence may trigger family members to challenge medical recommendations, resulting in delays of necessary treatment, withdrawal of unnecessary or non-beneficial treatment, or disposition. Families are primed for unexpected events BICU environment, and expectations for patient prognosis, family roles, clinician responsibilities, and potential decisions to be made are set forth in the hopes of alleviating clinician-family conflicts.

Family problems identified

A number of recurring themes present themselves in relation to patient and family dissatisfaction. Topping this list is exchange of information: physicians both underestimate the amount of information desired by patients, and rarely seek information from patients during clinic visits (Robins, Witteborn, Miner, Mauksch, Edwards, & Brock, 2011), indicating an undervaluing of patient communication.

As patients progress through the recovery process they face a number of transitions: in the BICU, the most notable of these are transition from intensive care to stepdown, and finally disposition.

Secondary transitions might include weaning from the respirator, regaining mobility, or a major surgery.

As the patient transitions, often times so must the role of the family. For instance, when a patient is

nonresponsive, the primary role of the family is to be present and communicate with physicians, providing relevant information and making necessary decisions; later, once the patient is awake, the role of the family involves interaction with the patient, monitoring them for pain or new symptoms, and communicating on their behalf with the health team; towards the end of their stay families can assist with recovery by helping the patient with daily activities such as feeding or dressing, and can help the patient make plans for care following disposition. All transitions, but especially disposition, can be particularly difficult for patients and family members, and adequate support from the healthcare team is crucial during these times (Davis, Devoe, Kansagara, Nicolaidis, & Englander, 2012).

Restricting visitation can be a source of conflict between clinicians and families. In burn units families are often asked to leave during wound dressing changes because clinicians assume seeing the condition of the patients wounds will cause family members distress; on the contrary, families reported greater anxiety and less satisfaction when visitation was restricted, and these families were less prepared to provide ongoing care following the patient's disposition (Bishop, Walker, & Spivak, 2013).

In a survey of 624 family members of patients in one of six university affiliated critical care units across Canada, families responding to questionnaires about the overall ICU experience, communication, and decision making reported the least amount of satisfaction with waiting room atmosphere and frequency of physician communication (Heyland, et al., 2002).

Family centered solutions

A myriad of clinician-family communication components have been identified as family centered, either in observational or intervention studies. Physician listening has been demonstrated to improve diagnosis and enhance physician-patient relationships (Jagosh, Donald Boudreau, Steinert, MacDonald, & Ingram, 2011). Increased proportion of family speech during family conferences about end of life care was related to increased family satisfaction with physician communication and decreased family ratings of conflict with the physician, regardless of the time spent in conference (longer conference times had no

effect). On average, physicians spoke 71% of the time and families speech made up 29% (McDonagh, et al., 2004). Physician communication styles characterized as "caring" were associated with increased patient satisfaction (Cousin, Schmid Mast, Roter, & Hall, 2012). Use of patient-centered communication scripts in recommending bypass surgeries resulted in increased ratings of competence and trustworthiness, and greater willingness to accept evidence-based recommendations (Saha & Beach, 2011). Setting expectations for treatment processes, efficacy, and timeline for finding appropriate medications at the outset of treatment resulted in increased patient perceptions of physician expertise and trustworthiness (Ledford, et al., 2010). In a coded transcript analysis of clinical communication, observers identified proactive transparency in communication as facilitating patient understanding and supporting autonomy, informed decision making, and relationship development, addressing patient uncertainty, and demonstrating empathy and respect (Robins, Witteborn, Miner, Mauksch, Edwards, & Brock, 2011). Incorporating families into patient care provides opportunities for social support for the patient, empowers families to advocate for patient needs, and eases the care burden for nurses. Regarding family-centered protocols, families of burn patients who were present during wound dressing were better educated about burn care at the time of disposition, and more confident in their ability to provide ongoing home care assistance (Bishop, Walker, & Spivak, 2013). In general, patients report the higher degrees of satisfaction with nursing skill and confidence, and variables significantly associated with satisfaction were completeness of information received, respect and compassion shown to the patient and family member, and the amount of health care received (Heyland, et al., 2002).

Problems with implementation

Patient- and family-centered care is grounded in the key concepts of respect and dignity, information sharing, participation, and collaboration, and is considered central to the ethical delivery and planning of contemporary health care. While the vision of patient- and family-centered care is already widely embraced, continued efforts are required to improve its implementation in practice.

Despite the efficacy of family-centered communication interventions in trials, clinicians' inability or unwillingness to comply with learned techniques presents an ongoing challenge. A study comparing nurses practices and perceptions of family-centered care revealed that, though the majority of nurses endorsed family-centered care beliefs, that did not implement family-centered principles in practice, citing their own inability to practice family centered care, the hospitals lack of support for family-centered practices, and perceptions of their caregiving roles that were inconsistent with family-centered care goals (Bruce & Ritchie; Journal of Pediatric Nursing: 1997). In another study, a communication training course designed to help nurses handle difficult communication situations improved self-efficacy in a randomized controlled design comparing pre- and post-training measures, however measures of performance pre- and post-training were unchanged (Doyle, Copeland, Bush, Stein, & Thompson, 2011).

Implementation of family-centered care as an "add-on" to current practice is an overly simplistic model, in that it fails to address inconsistencies between standard practice and family-centered care. For instance, family-centeredness assumes equality in collaborative relationships between families and clinicians; in contrast with the expert model of treatment, which presumes clinician use of value-neutral, evidence based best practice standards. Moreover, family-centered literature overlooks heterogeneity within the clinician team that arises from specialization; it assumes a common perspective from all clinicians that must be merged with family perspectives, when in fact the medical team itself represents a diversity of opinions and values (Lawlor & Mattingly, 1998).

Asymmetry in doctor-patient relations is commonly cited as a source of dissatisfaction. As such, these interactions have been the targets of interventions since the 1960s, and most current physicians have received some form of patient-centered communication training attempting to refine physician approaches, making them more equivalent to patient roles. Nevertheless, asymmetry persists, and according to social science researchers: "the evidence that 'patient-centeredness' has a positive impact on health outcomes is at best mixed" (Pilnick & Dingwall, 2011). These outcomes together highlight the inadequacy of communication-based training interventions at effecting change in doctor-patient interactions.

Measurement

Satisfaction. Family-centered care literature has broadly used patient or family satisfaction as a proxy for the measure of successful implementation of patient- and family-centered programs and strategies. Research in critical care has demonstrated increases in family satisfaction associated with higher frequency of physician-patient communication; (Heyland, et al; Critical Care Medicine: 2002); higher levels of family speaking during physician-family communication events—also characterized as increased listening by the physician (Clarke, et al; Critical Care Medicine: 2003); family incorporation during rounds, and endorsement of shared decision-making (Davidson, et al; Critical Care Medicine: 2007). Empirically designed communication interventions (Curtis, et al; Critical Care Medicine, 2001); and training in communication (Helitzer, et al; Patient Education and Counseling: 2011) have been demonstrated to improve patient satisfaction measures.

Trust. Satisfaction has been challenged as an adequate measure of patient centered care. For instance, a conceptual analysis by researchers at Wake Forest University found trust to be more instrumental as a construct for predicting avoidance of conflict (Hall, Dugan, Zheng, & Mishra, 2001). Trust is also predictive patient involvement in medical care, in terms of attitude toward seeking care, participation in decision making, and adherence to treatment recommendations (Trachtenberg, Dugan, & Hall, 2005). Trust and satisfaction may not be entirely distinct concepts, as both are predicted by amount of time spent with the provider and the patient's ability to choose the provider; however, trust is uniquely predictive of patient's desire to seek care, and their desired degree of physician control in medical decision making (Balkrishnan, Dugan, Camacho, & Hall, 2003).

Quality indicators. The Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup evaluated fifteen adult medical intensive care units representing thirteen states and Canada. Specific clinician and organizational behaviors and interventions that contributed to quality end of life care were identified. Quality indicators in end of life care were characterized within seven domains: patient- and family-centered decision making, communication, continuity of care, emotional and practical support, symptom management and comfort care, spiritual support, emotional and organizational support

for intensive care unit clinicians (Clarke, et al., 2003).

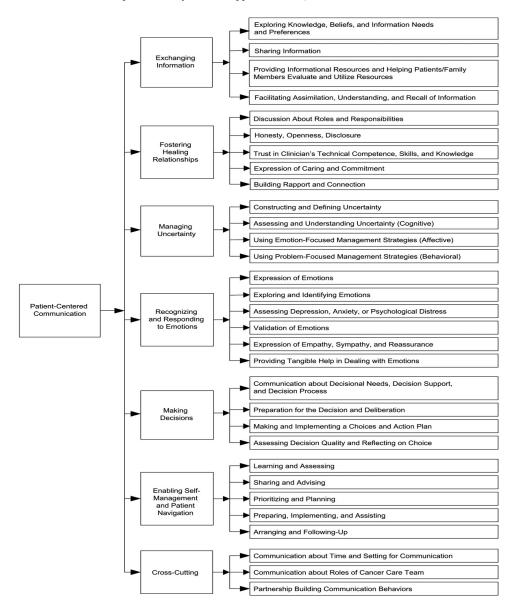
Communication – a functional measure. One criticism of satisfaction as a measure of family centered care is that, since satisfaction is generally based on patient or family self reports or on observations of patient/family responses, it does not separate the clinicians actions from the patient's or family's evaluations of them (McCormack, et al., Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach, 2011), foreclosing prescriptive conclusions about specific behaviors. Families may have implicit expectations of clinicians, or conceptions of the social contract that differ widely (Lawlor & Mattingly, 1998), so satisfaction could be largely dependent on clinician adherence to preconceived notions, rather than they're willingness to incorporate the family and take family perspectives into account. Since the Institute of Medicine in the USA in 2001 called for improvements in healthcare, which included a recommendation for patient centered care, an objective measure of patient centeredness has been sought. Communication is central to family centered care. A systematic approach to measuring patient centered communication has been proposed to provide a functional, rather than evaluative, measure of patient centeredness (McCormack, et al., Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach, 2011). A conceptual model of patient centered communication developed by the U.S. National Cancer Institute consisting six distinct domains relating to healthcare outcomes: responding to emotions, exchanging information, managing uncertainty, making decisions, enabling patient self-management, and fostering healing relationships (Epstein & Street, 2007), served as a basis for this approach (Figure 2).

Social Cognition

Literature concerning communication in health care reveals two separate domains in terms of communication content and function: that which is cognitive—related to information that must be collected by the physician, translated for the family, and jointly used in decision-making; and that which

is social—related to the emotional state of the family, and the emotional character (or lack thereof) of information presented by clinicians to the family. Communication between families and physicians is essential in critical care, but is frought with conflict and misunderstanding. This section addresses physician and family differences in social cognition that may influence interpersonal communication, providing insight into the nature of conflicts that arise between physicians and family, and potential targets for communication interventions.

Figure 1. Patient-centered communication (McCormack, et al., Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach, 2011).



Communication

Communication between families and clinicians is considered central to family centered care (McCormack, et al., Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach, 2011). Effective communication becomes even more crucial in critical care when family surrogates must participate in decision making on behalf of patients, resulting in improved medical decision making and better outcomes for both the patient and the surrogate. A conceptual model of communication in surrogate decision making incorporated domains of information processing and relationship building. Information processing included the subdomains of information disclosing, sense making, and expectations; and relationship building included the subdomains of emotional support, trust, concensus/conflict, and roles/participation (*Figure 2*). In this model information processing and relationship building were considered key factors in high quality medical decisions, which were characterized as informed, concordant with values, and mutually endorsed (Torke AM, 2012).

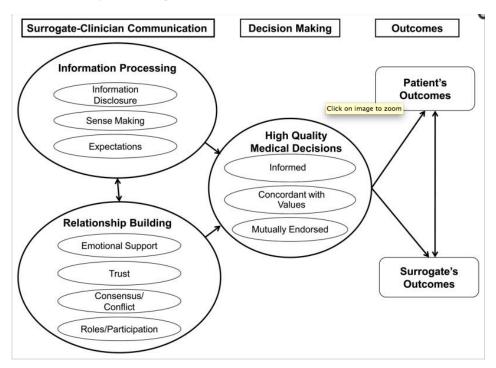


Figure 2. Conceptual Model of Communication (Torke AM, 2012)

Dual processes in social cognition

Dual process models of social cognition have long been foundational to social psychology. Dual processes modeling serves to explain the ways in which information processing differs in relation to conspecifics (members of the same species). Information of a social nature, such as identification of conspecifics, characterizing facial expressions, detecting threat or non-threat based on body positioning, and in humans, detecting irony or emotive content based on vocal prosody, and detecting deception based on eye movement, are examples of information that is acquired automatically, without deliberate attention or specific training; this automatic processing is termed *reflexive*. In contrast, purely non-social cognitive information acquisition relies on focused attention, repetition, prolonged exposure, and intentional rehearsal; such controlled processes constitute *reflective* cognition (Loewenstein, Rick, & Cohen, 2008).

Dual process models of automatic/reflexive and controlled/reflective processing have been proposed in nearly every domain of social psychology. The dual process approach is widely accepted by both cognitive and social psychologists, and recent work in cognitive and social neuroscience has provided functional evidence to bolster a history of behavioral findings. Reflective processes involve awareness, intention, effort, and the capacity for interruption; reflexive processes lack at least one of these qualities (Lieberman, 2007).

Table 5. Features associated with X- and C-system (Lieberman, 2007)³

X-System	C-System
Parallel processing	Serial processing
Fast operating	Slow operating
Slow learning	Fast learning
Nonreflective consciousness	Reflective consciousness
Sensitive to subliminal presentations	Insensitive to subliminal presentations
Spontaneous processes	Intentional processes
Prepotent responses	Regulation of prepotent responses
Typically sensory	Typically linguistic
Outputs experienced as reality	Outputs experienced as self-generated
Relation to behavior unaffected by cognitive load	Relation to behavior altered by cognitive load
Facilitated by high arousal	Impaired by high arousal
Phylogenetically older	Phylogenetically newer
Representation of symmetric relations	Representation of asymmetric relations
Representation of common cases	Representation of special cases (e.g., exceptions)
	Representation of abstract concepts (e.g., negation, time)

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³ Table titled Features associated with X- and C- systems posited to support reflexive (analogous to automatic) and reflective (analogous to controlled) processes. Adapted from Satpute and Lieberman (2006).

Distinct neurocognitive systems have been postulated to support these distinct systems of social cognition. The *X-system* (so named for the x in reflexive) corresponds to automatic social cognition, and consists of the amygdala, basal ganglia, ventromedial prefrontal cortex (VMPFC), lateral temporal cortex, and dorsal anterior cingulate cortex (DACC). The *C-system* (for the c in reflective) corresponds to controlled social cognition, and consists of the lateral and medial prefrontal cortex, lateral and medial parietal cortex, medial temporal lobe, and rostral anterior cingulate cortex (RACC). The rational for assignment of neural components to the X or C system is provided in the table below (Satpute & Lieberman, 2006).

Table 6. Rationale for components of X and C systems

Table 6. Rationale for components of X and C systems X-System		C-system		
Amygdala	 Fear Reward Fight-or-flight Subliminal representations Modulated by anxiety Robust response despite intentional modulation 	Lateral PFC	Effortful Resource-demanding cognitive tasks Symbolic representation Working memory Reasoning and logic Fluid intelligence Analogy Problem-solving Asymmetrical/unidirectional (causal) reasoning	
Basal ganglia	Affect Cognition Behavior Implicit learning Probabalistic learning Motor skill learning Slow to acquire Fast to execute	Medial PFC	Self and social cognition Cognitive load-dependent Evolutionarily advanced (larger in primates)	
VMPFC	Long-term formation of automatic intuitions Implicit gender stereotyping Framing effects Capitalizes on intuitive over deductive reasoning	Medial temporal lobe	Directed memory retrieval Conscious recollection of past learning episode Fast, flexible learning Sparse representational coding scheme Overrides slow, habitual learning	
Lateral temporal cortex	Semantic and conceptual processing Contructing stereotypes Individual impressions Dispositional attributions Face recognition Action recognition Positing intentions Translating body motion Interpreting eye gaze Imputing goal states	Posterior parietal cortex	Self-focused attention Perspective-taking	
DACC	Emotional distress Physical and social pain Automatic alarm system; alerts C-system to respond to novelty	rACC	Conflict detection Error processing	

Social cognitive processes are at the core of understanding and regulating oneself, and understanding and interacting with others. Understanding with others includes the ability to represent the minds of others, known as theory of mind; and the ability to experience the mental or emotional states of others, also known as empathy. Understanding oneself entails experiences of agency, reflection on

current or past experiences, and reflecting on one's self-concept; and regulating oneself involves impulse control, cognitive reappraisal, and emotional regulation. Social interactions incorporate attitudes and prejudice, social connection and rejection, social and moral decision making, and conceptions of fairness and trust in relationships (Loewenstein, Rick, & Cohen, 2008).

A social cognitive theory-based intervention design is a novel approach in healthcare communication. The importance of cognitive and behavioral theoretical approaches to intervention design has been demonstrated in health psychology for applications such as smoking cessation (Fishbein & Cappella, 2006), and relapse prevention in alcohol and substance use disorders (Wietkiwitz, Marlatt, & Walker, 2005). However, the use of principles of social cognition in intervention design has been confined primarily to clinical psychology and neuropsychology, in the contexts of communication training (Aldred, Green, & Adams, 2004), social skills training (Wallace & Liberman, 1985), and cognitive training (Sammera, Reuterc, Hullmanna, Kapsd, & Vaitlb, 2006) in disorders as diverse as autism, schizophrenia, and dementia due to Parkinson's disease. The purpose of these interventions is to counteract communication deficits and to restore functional and effective communication. While physician and family communication problems bear little resemblance to the specific deficits incurred in these disorders, it would not be controversial to suggest that physician-family conflicts arise due to communication that is dysfunctional and/or ineffective. Thus, designing theory-based interventions to target areas in which physician-family communication departs from accepted norms and ideals is a logically founded approach.

The neuroscience of empathy

Studies in cognitive neuroscience have revealed physician empathy toward patients in pain is diminished compared to non-physicians. Functional neuroimaging has been used to demonstrate that viewing another person experiencing pain activates brain regions associated with pain processing, including the somatosensory cortex, regions of the anterior cingulate cortex, the anterior insula, and the periaqueductal grey—a primary site of pain transmission and anxiety and fear processing. The result is a

kind of empathic mimicry of pain, which is experienced as generally aversive. Somatic sensorimotor resonance in pain areas can elicit sympathy and concern, however they can also signal threat, resulting in personal distress and anxiety. For healthcare workers who continually see patients in pain, and may inflict pain during the course of care, chronic arousal of this kind can be costly, both physiologically and cognitively, potentially resulting in compassion fatigue and burnout and interfering with care delivery (Decety, Yang, & Cheng, 2010); or contributing to anxiety and depression among care providers (Penson, Dignan, Canellos, Picard, & Jr., 2000). Functional neuroimaging (fMRI) has demonstrated that physicians respond differently than controls when exposed to visual pain stimuli (in this case, a video of a person's hand or foot being pricked with a needle), while there was no difference in processing when watching non-painful stimuli (hand or foot being touched by q-tip). Signal changes when physicians switch from watching non-painful to painful stimuli reveal an activation of cortical regions that underlie executive functions, self-regulation and executive attention—associated with regions of the prefrontal cortex and temporo-parietal junction, respectively—which are not seen in controls. Moreover, activation of pain regions was diminished in physicians; three of the pain regions that were activated in controls in response to viewing painful stimuli were not activated at all in physicians (Cheng, et al., 2007). These results indicate that physicians engage in both bottom-up inhibition of perceptual pain processing, as well as top-down regulation of responses to others' pain. (Decety, Yang, & Cheng, 2010).

Event related potential (ERP) studies have demonstrated pain empathy as consisting of two separate, temporally differentiated responses: an early emotion-sharing phase, and a later cognitive appraisal. A follow up to the fMRI study compared dispositional measures, visual analog reports of pain intensity and unpleasantness, and ERP recordings of physicians versus controls. Physicians and controls did not differ on dispositional measures, which included measures of emotional contagion, interpersonal reactivity, empathic concern, perspective taking, personal distress, and situational pain. However, physicians did report significantly lower pain intensity and unpleasantness in response to visual pain stimuli. While ERPs of controls were differentiated in response to pain vs. non-pain conditions in both early and late phases, physician ERP measures were not differentiated in either phase; indicating that

physicians modulate pain perception in both the automatic emotion-sharing phase, and the late cognitive evaluation of pain empathy (Decety, Yang, & Cheng, 2010).

In summary, dampening down of the physician responses to patients' pain is both an intrinsic effect of medical expertise, and likely operates as a coping mechanism for physicians to maintain the cognitive resources and emotional stability necessary for practicing medicine. The effects of downregulated pain empathy in practice aren't immediately clear, however the findings warrant concern, particularly in the context of pain management (Decety, Yang, & Cheng, 2010). Moreover, inhibitory processing of pain may have resounding effects; inhibitory processing is associated with a stress response, with increased sympathetic and cardiovascular activity, and has been demonstrated to inhibit memory ability for social information (Gross & Levenson, 1993). In addition, this type of emotional regulation may be particularly stressful for both the physician and the family in the context of interpersonal communication (Butler, Egloff, Wilhelm, Smith, Erickson, & Gross, 2003).

The neuroeconomics of decision making

The study of neuroeconomics brings together the once disparate fields of economics and psychology, informing both fields in different ways. Arguably the greatest contribution of neuroeconomics has been to our understanding of decision making. A traditional economic approach viewed human decision making as a unitary, logical, coordinated approach aimed at maximizing utility. Neuroeconomics relies on an array of tools, including blood oxygen level dependent (BOLD) signals from fMRI recordings, positron emission tomography (PET), electroencephalography (EEG), magnetoencephalography (MEG), near infrared spectroscopy, anatomical imaging, transcranial magnetic stimulation (TMS), and lesion studies, genetics, pharmacology, and neurotransmitter loading or depletion, to provide information about brain function associated with various behaviors or cognitive tasks (Kable, 2011).

Neuroeconomic findings reveal an understanding of decision making not as a single, goaloriented process, but rather the sum of a number of nonlinear processes, some working in opposition to one another, that are differentially weighted and vary in value situationally. Neuroeconomics provides further support for dual processing, and provides insight into differences between how physicians and family members engage in decision making and expectation development. Beyond obvious differences in education (physicians rely on medical training and families generally do not), differences in emotional state, exposure to similar experiences, personal knowledge and relationships, and goals and priorities will all emerge as factors differentially influencing physician and family thought processes and communication.

Cultural transmission

Cultural transmission is the fundamental means by which dispositional preferences, attitudes, cultural traits, social norms, and ideologies are developed. The evidence of cultural transmission is most salient in the resilience of ethnic and religious traditions over time. Cultural transmission occurs both in a direct vertical manner as a result of explicit socialization, as well as by implicit forms of social learning and imitation that are crucial to identity (role) formation (Bisin & Verdier, 2011). In the BICU, rounds represents vertical cultural transmission by the attending; horizontal and oblique cultural transmission occur when new residents adopt the attitudes or behaviors of senior physicians (whether intentionally or not) in order to gain acceptance.

In healthcare, enculturation (or, cultural transmission via organizational socialization) is a lengthy process. Following medical school, an additional 7 to 12 years of technical training in either medical or surgical specialty is required for a physician to become certified as a specialist. A study at the Mayo Clinic revealed that it takes at least 5 years for new physicians to be completely "socialized" into a new organization. The end results of the socialization process for physicians include improved job satisfaction, improved commitment to the organization, and decreased likelihood of leaving the organization. Physician satisfaction is also related to patient satisfaction, as well as commitment to the medical group. Hence, efficient physician socialization is in the best interest of healthcare administrations, clinicians, and patients alike (Pitts, 2009).

Rites of passage serve as tools of enculturation, such as the rite of residents "presenting the case." Presenting the case is a fundamental ritual of resident socialization that occurs during rounds, in which residents are called upon to provide a medical synopsis of each patient's condition, including factual information about the diagnosis and treatment, as well as current test results, symptoms, responses to medication, and so forth. The resident is then questioned (or quizzed) about details of the patient's case, and corrected by the attending or other senior physicians as needed (Hobbs, 2004).

Progress notes are another form of socialization for residents. Progress notes, distinct from nurses notes, document the information from case presentations as well medical history and procedures. Although they occur in a less formalized setting (residents will add information to progress notes throughout the day), residents assimilate expectations about progress notes in a number of ways. Pamela Hobbs of UCLA describes the process by which progress note socialization occurs:

"The process by which residents learn to write these notes in most cases involves little or no direct instruction; instead, they learn by modeling. Residents study and review the notes of other physicians—particularly those of residents senior to themselves—in order to familiarize themselves with the pragmatic and cognitive structures that typify this professional genre. Moreover, as members of the treatment team, consisting of attendings, residents, nurses, and other medical personnel responsible for the ongoing care and treatment of patients on the unit, residents are exposed to the continuous influx of information transmitted to them by the collegial talk and chart notations of other treaters, all of which serves to inform and clarify their own observations and judgments."

Researchers from the University of Pennsylvania investigated how policy changes that limited work hours for residents had the unintended affect of altered surgeon socialization. While the policy was intended to improve safety by reducing adverse events related to sleep deprivation, reduced work hours resulted in a significant shift in the formation of surgeon's occupational identity, creating a generational rift, as well as a social divide—residents tended to respond positively to the policy, while surgical faculty disapproved (Brooks & Bosk, 2012). Because no actual decrease in mortality was noted after work hour restriction was put into place, it is possible that potential safety gains were offset by impaired socialization of new surgeons. This example serves as a warning that the culture in any hospital unit

represents a dynamic system—a delicate balance which can be disrupted by the introduction of new policies.

Systems Integration

Systems integration is a process of improving safety and quality native to the aviation industry. In healthcare, despite numerous interventions aimed at improving patient safety (in terms of morbidity and mortality) and improving care provided (some measures included patient and physician satisfaction and retention), little progress has been made in this area. A systems integration approach is needed to address the complexities that exist in healthcare, and particularly in provided critical care. Lack of integration can lead to diagnostic errors, problems in communication, inefficient processes, resulting in a stressful environment for clinicians associated with caregiver burnout (Matthews & Provonost, 2011).

Drawing from systems integration theory, addressing the problem of miscommunication between the family and medical team requires an examination of the variety of factors which work together (or, at times, against one another) within the burn unit system, and in the context of their environment. Thus factors regarding the patient, family, medical team, and hospital environment must all be evaluated in terms of their interactions within the context of the provision of care within the burn unit.

Patient factors may include current condition, health condition prior to admission, potential for recovery, changes in level awareness throughout the course of care, and future need for personal care assistance following disposition. Family factors may include the closeness of relationships between family members and the patient; roles and responsibilities if surrogate decision-making is required; work requirements and transportation resources, as related to their ability to visit the patient during the course of hospital stay; barriers to communication with the medical team, including language or educational limitations, as well as lack of resources such as access to a personal phone by which they may be readily contacted. Medical team factors include communication interactions and distribution of authority between various team members, i.e. attending physicians, residents, nurse practioners, charge nurses, and

bedside nurses. They also include factors particular to these individuals, such as communication skill, availability to communicate with patients (as a function of other responsibilities), empowerment to communicate relevant information to family members, and prioritization of various duties. Environmental factors might include adequate staffing, access to resources, and training in patient- and family-centered approaches.

Such factors cannot be evaluated in isolation, as changes within any particular area necessarily influence others in ways that are not entirely predictable. The Vanderbilt Regional Burn Center must be evaluated as a system to determine which elements are modifiable, and which modifications would result in improved patient- and family-centered outcomes. Systems integration concepts of will serve as a guideline for intervention development and implementation.

CHAPTER IV

RESULTS

General Observations: The Big Picture

Defining expectations

clinicians and families have? What are they about? Who influences expectations for whom? Clinician and family expectations were analyzed in the context of a dynamic system, consisting of activities and communication occurring within the BICU environment. While each element of the system plays a role

General observations served to answer the following questions: What kinds of expectations do

in expectation development, the predictable interaction of the system as a whole plays a pervasive role in

expectation development as well.

Routine expectations

The primary intent of general observations was to gain an understanding of how expectations

about critical care are developed. Because the aim of the study was to address family crisis

communication events—the primary object of ethicist interventions in critical care—efforts were made to

identify events, behaviors, or structural issues influencing clinician and family expectations. Roles,

times, activities, and locations associated with current communication about expectations are evaluated,

with an eye toward establishing prospective roles, activities, times, and locations suitable for interventions

with families. In short, the general observation phase answered the questions of who, what, when, and

where regarding critical care communication about expectations in the BICU—and by extension—

regarding potential interventions. The integration of the dimensions who, what, when, and where (Table

3.1) results in a dynamic system.

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Table 7. Four Dimensions of BICU Expectation Dynamics: Who, What, When, and Where

Who: the key players in expectation development

- Clinician—develops expectations about the patient, the family, and each other
- Family—develops expectations about the patient, themselves, and clinicians

What: the kinds of expectations that are being formulated

- Expectations about patient survival
- Expectations about future course of care
- Expectations about patient / family outcomes
- Expectations about clinician / family roles
- Expectations about communication

When: the time frame for which expectations are relevant

- Daily care
- Long-term care

Where: because critical care activities are closely tied to particular areas within the unit, and these activities occur within a structured daily routine, this category interchangeably refers to activities, locations, and routines in which expectations are constructed, developed, or communicated

- Pre-rounds
- Rounds
- Interdisciplinary rounds
- Floor
- Waiting room
- Phone call / home visit

The changing of seasons: Patient progress expectations

Phase I - Resuscitation. Patients are admitted to the BICU when they require emergency care in response to very severe burns and smoke inhalation. Typically, for the first twenty-four to forty-eight hours the patient's condition is instable and survival is uncertain; the majority of patients who die in the BICU do so within this time period. It is not unusual for a patient to suffer cardiopulmonary arrest (referred to by clinicians as coding) requiring emergency resuscitative efforts several times before finally being stabilized, hence this is referred to as the resuscitation phase. During this phase, nurses remain vigilant attending to the patient, and physicians rush in and out assessing the patient's condition, investigating the patient's medical records, and researching case histories. Family is often not present during this phase, because patients have typically been brought in by ambulance or helicopter; families may have to travel long distances, as the VRBC is the primary burn treatment center for several surrounding states.

If families are present during this time, a **medical receptionist** will speak with them to obtain insurance information and urgently needed medical history of the patient, including the source of the burn—e.g., grease splatter, chemical burn, oxygen tank explosion, etc.—which is important to understanding burn severity and making treatment decisions, the patient's health condition prior to the burn, current medications prescribed or other drugs taken, known allergies, and whether the patient was a smoker—a question that is asked in medical histories taken for almost any reason, but is especially critical with burn patients for physicians to understand the extent of lung damage due to the burn, versus lung damage due to smoking, and the prospects for treatment and recovery. After the medical receptionist has obtained all necessary information, patients are asked to wait in the waiting room. Patients generally do not hear from a clinician regarding the patient's condition until the patient is stabilized; they may wait for several hours before finding out whether the patient has survived.

Phase II – Rehabilitation. Once the patient is stable, the *rehabilitation phase* begins. The patient is still in critical condition. For the next three to ten days, clinical efforts will focus on ventilation

changes to promote lung healing; maintenance of sufficient blood pressure, lowering heart rate, and increasing organ perfusion to prevent shock; maintenance of hydration and lowering of internal body temperature to avoid delirium; treatment and prevention of infection; and pain management. Although survival rates increase following stabilization, death is still often times not preventable, and physicians typically do not offer prognosis to the family at this time. Within the team, prognosticating is fairly common, based on heuristics that take age of patient, prior health condition, and percentage of burn into account. Many burn patients have fairly complicated medical histories, making accurate prognosis and treatment more difficult.

Family members who are present at this time may be unable to visit the patient due to the severity of their condition; when circumstances do allow for visitation, a specific sanitation protocol is required to prevent contamination, as burn patients are severely immunocompromised. Families may play a role in monitoring patient condition and reporting changes to nurses, and they are especially beneficial in interpreting expressions of pain or discomfort in the context of the patient's prior health.

Family members who are present at this time may be asked to make treatment decisions, as the patient is in most cases still nonresponsive; patients may not have regained consciousness due to extensive brain damage, or may require medications that interfere with consciousness or the ability to communicate. If the patient fails to progress, the family may be asked to make decisions regarding treatment withdrawal.

Phase III – Recovery. Once the patient's condition has improved significantly, ventilation and medication protocols fluctuate less rapidly, and burn care becomes a primary target. Hydrotherapy, skin grafts, and wound dressing are the most essential tools of burn wound healing. Some patients also require reconstructive surgeries or organ transplants. Pain management and prevention or treatment of infection are still crucial during this stage, and changes in pharmaceutical regimens are often required with every surgery or treatment. During recovery, infection is the most likely cause of death.

Patients in the recovery phase have generally regained consciousness, however some remain unable to communicate either due to brain damage, damage to speech organs, or sedating medications. Families are generally encouraged to visit the patient during this phase, which is often associated with improved patient experience and quicker recovery. Families also play an important role aiding patients in making treatment decisions, and communicating patient symptoms and needs to clinicians.

Phase IV - Stepdown. Once all major surgeries are complete, medication regimens have stabilized, and progress has been made with wound healing to the extent that the patient's condition is no longer considered critical, patients are transitioned to the stepdown unit adjacent to the ICU. Goals of care include medication maintenance, continued wound care, and improving patient functioning in preparation for disposition. Nurse practitioners conduct interdisciplinary rounds in the Stepdown unit with physical therapists, occupational therapists, social workers, and other allied health care providers. Medical and surgical attending physicians may join interdisciplinary rounds as needed to oversee patients under their care. Family involvement is especially important in helping patients maintain morale. Compared to other critical care units, burn recovery is lengthy; because the patient's health has improved significantly, a nurse is no longer present full time in the patient's room, so families can provide company for patients who may otherwise feel isolated. Families can also assist patients with basic care needs, such as feeding, bathing, dressing, or toileting, allowing greater comfort for patients who may otherwise have to wait for a nurse to become available. Families who are present in Stepdown can also learn to assist patients with burn care, by dressing and splinting wounds; and with physical and occupational therapy goals, by providing physical support to patients as they perform exercise techniques, and by providing motivation and encouragement. Patients with families present tend to progress more quickly and have shorter stays. Families who learn to provide basic care while the patient is in Stepdown are better prepared to assist patients with follow up care after disposition, improving patient adherence to clinician recommendations and ongoing recovery.

Family issues

Compared to other hospital units, the BICU admits a significantly higher number of patients of low socioeconomic status (SES). Families of such patients often have lower levels of education, and are less likely to speak English as a primary language, which may result in an inability to obtain accurate or complete medical information. Families of low SES patients are more likely to be absent, often due to financial constraints (inability to travel or to miss work), or because patients have severed or very weak ties to family, and insubstantial social support.

Focused observations

Expectation development

The most salient themes influencing critical care expectations in the BICU were 1) professional/social hierarchy of healthcare providers; and 2) functional/social division of physicians and nurses; 3) clinician expectation sharing: consensus, uncertainty, and contingencies in formulating prognosis and care plans; 4) nonparallel priorities in planning: prevalence of daily care updates / information, and relative absence of long term planning information in messages from clinicians to families; and 5) clinician / family incongruence in time and space: dis-chronicity between clinician and family time spent with patient, and lack of "shared space" for clinician-family communication.

Healthcare hierarchy: Messages from above

Enculturation is one of the most pervasive ways in which expectations are transmitted in a top-down fashion within the healthcare heirarchy. The **critical care director** serves as the chief executive for the BICU, and a **medical director** serves in this capacity for the Stepdown unit. These physicians are at the pinnacle of their careers; they rely upon their years of experience and training to establish guidelines and protocols for the entire VRBC. They are in charge of policy formation, quality assurance, and ethics enforcement. As such, they shape expectations for the unit in a very pronounced and direct

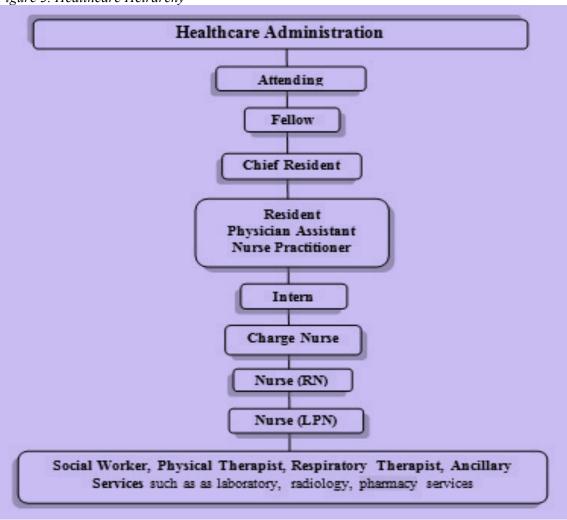
fashion. However, there are also influencing expectations for clinicians in indirect ways, by virtue of the types of ongoing training they require (such as family-centered communication training), the nature of the incentives or sanctions they put into place (whether they are fiscally vs. socially driven), the selection of an attending physician, and the latitude that is given to the attending in terms of jurisdiction and behavior.

The **critical care attending** plays the most dominant role in enculturation of expectations in the BICU. Directly, the attending is responsible for overseeing all clinical decisions and procedures within the unit: prognosis, treatment goals, daily care, clinical tests, medications, rehabilitation, and even visiting priveleges fall within the attending's discretion. As the attending is responsible for assigning physician duties, training new residents, and teaching medical students, the future careers of physicians depend upon favorable reviews by their attending physician. Ideally, the attending is present during all major procedures, and is ultimately culpable for all care decisions. Attending physicians from other specialties are called in for consultations with complex cases.

Fellow physicians are frequently appointed oversight duties when the attending is not present, and fellows delegate authority to chief residents as needed. Fellow physicians provide delegate responsibilities to residents and aid in training. Chief residents may act in supervisory roles when appointed by the attending or fellow, and aid in training residents and medical students. Chief residents are expected to display expertise in their specialty during rounds, and demonstrate exemplary clinical and cultural behavior. Residents are often questioned by chief residents, fellows, and the attending during rounds, as a means of testing their medical knowledge of a particular subject, or their familiarity with the patient's current "numbers"—clinical measures of the patient's condition, including oxygen saturation, blood pressure, and organ perfusion, among others. Residents interactions with senior physicians tend to involve approval-seeking, rather than information-seeking. Information-seeking that is medical in nature tends to be done independently or among resident colleagues, and information-seeking that is patient-specific is often garnered from nurses. Residents display both cooperative and competitive toward one another. Residents come to rounds equipped with a walk-around computer, giving them access to the patient's electronic medical record, as well as medical knowledge databases to research unknown

conditions and treatment regimens and to obtain case reports. Throughout the day, residents tend to congregate on "the floor" (an open area central to all patient rooms) at a centralized workstation—a large, stylized multi-person desk supplied with an array of computers, patient files, case reports, and lab results. Residents also use mobile computer stations, which they bring to rounds to document patient information and refer to medical history, lab results, and related literature.

Figure 3. Healthcare Heirarchy⁴



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⁴ Image retrieved from http://3.bp.blogspot.com/_0tisbadydnk.../hierarchy+graph+pic.jpg

The great divide

Though they work side by side, physicians and nurses manage to remain surprisingly segregated socially, functionally, and ideologically. In a study to determine the attitudes and practices of pediatric critical care attending physicians (n=110) and nurses (n=92) on end-of-life care also revealed that physicians were more likely than nurses to report that families were well informed about the advantages and limitations of further therapy (99% vs. 89%); that ethical issues are discussed well within the team (92% vs. 59%), and that ethical issues are discussed well with the family (91% vs. 79%) (Burns, Mitchell, Griffith, & Truog, 2001).

In the BICU, residents and **nurse practitioners (NP)** have approximately equivalent clinical roles, however their functional roles in practice are not interchangeable. Besides the morning rounds in the BICU, NPs and residents work in completely separate spaces: residents remain in the BICU, and NPs are primarily responsible for patients in Stepdown. Residents commune throughout the day at a centralized location, collaborating about the patient and socializing; conversely, the NP—in between checking in on patients and getting updates from nurses—spends most of her day in a solitary office, away from the patient wards.

NPs attend BICU rounds with critical care physicians in the BICU. Because NPs also lead interdisciplinary rounds with consulting physicians and allied health care providers in the adjacent Stepdown unit, the NP is uniquely tasked with oversight of every patient within the VRBC, both those in the BICU and in Stepdown. As such, the NP is the *only* clinician who is knowledgeable of each and every patient's condition, and is responsible for the care of every patient in the unit. As a result, the NP carries a patient load that is double that of any other clinician in the unit. In addition, the NP is the sole provider who interacts with the patient all the way from intake to disposition. Consequently, it is the NP alone who shoulders the burden of continuity of care for the entire unit.

Charge nurses act as "shift supervisors" who are immediately responsible for all nurse activity;

CNs are in charge of all administrative duties for nursing staff, including coordinating schedules,

delegating duties, and assigning patients to bedside nurses (BN). BNs have the most direct involvement

with patients. Because BNs have no administrative duties; their sole responsibility is to attend to the patient's needs. In the BICU there is generally a 1:1 ratio of BNs to patients due to the intensive nature of care that is required, and BNs rarely leave the patient's side for more than a few minutes at a time to retrieve needed supplies, or report important changes in patient condition to an NP or resident. Bedside nurses also have the most interaction with family members as well, due to their constant proximity to the patient. Bedside nurses tend to be isolated from one another and from other clinicians for the majority of the day because they remain in patient rooms.

Collaborative construction of clinical expectations: Concensus, uncertainty, and contingencies

Concensus. The primary function of physician rounds is to achieve consensus regarding patient status and plan of care. Prior to rounds, physicians examine patients and identify issues that need to be resolved, or questions that need to be answered, in rounds. Residents review updates to the patient's chart, including lab and diagnostic test results (whole blood count, toxicology screen, arterial blood gas), radiology reports (chest x-rays of lung damage, MRIs to detect tissue perfusion), patient vital signs (physiological measurements of temperature, heart rate, blood pressure, respiratory rate, oxygen saturation), and nurses notes describing changes in patient symptoms or condition. Based on these assessments, residents will formulate tentative care plans. For complex issues, residents consult the current published case literature to gain insight from similar cases.

Focused observations⁵

■ #19 Fellow sees P's leg shaking and asks if P's in pain. BN says P back from hydro. F asks P about pain and anxiety, tells P they will give P something for pain, don't worry. A checks P's chart for meds--antibiotics and lab results. F asks A if ID has preference for antibiotic for P's illness. A looks up relevant literature, reports recommended dosage. F asks for clarification, "So they're advising double-coverage?" R clarifies dosage. A and F discuss possible antibiotics, order meds. A asks R what antibiotics P has already had. R checks chart, reports. A says to keep that med and add a new one used for this sort of infection in Burn Ps. Says to consult Pharm about what needs to be done.

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⁵ Focused observations are reported by assigned number for consistency. Family ID numbers and dates of observation have been omitted from this publication to ensure privacy.

During rounds, residents report patient status and proposed care plans to the team. Attendings respond by questioning the reasoning behind the care decision, by providing additional education to inform the care decision, or by asking other residents to either affirm or oppose the care decision and explain their reasoning. Attendings may also appoint fellows or other senior physicians at this time to correct or educate residents about specific details of the patient's case, based on their personal expertise or experience. Occasionally, physicians will ask the bedside nurse for information regarding the patient's symptoms, or the bedside nurse may volunteer information.

Focused observations

#18 F and BN present P's status update to A--P has been extubated and pressures are "weird." Fellow asks BN, "How're things going?" BN reports P's stats for day. BN tells F "I don't know why P isn't sat'ing well, oxygen stats are down. F says that P smokes but that wouldn't explain problem. F, F, and BN discuss mystery cause. Decide to turn oxygen flow up. F continues presentation to A: P's urine output is up. BN reports meds to team--maybe they're part of the saturation problem. F and A ask P to take a deep breath, ask if it's painful. A tells team that P should be awake and orders breathing test every few hours. A asks team about pain meds. P denied opiate use at home. P's potential drug use and known drug use discussed. F makes to do for BN about test for future. A asks about P sitting in chair--should that be a future goal? BN tells team that PT is planning to do this tomorrow.

Uncertainty. Often there is no clearly established protocol for dealing with complexities of patient care. The cause of unusual symptoms may be unknown, or physicians may offer differing recommendations for course of care based on their specialties, exposure to related research, or practice experience. Uncertainty is tolerated, and dealt with by plans to obtain further information, sometimes by evaluating the patient's response to a proposed treatment. Short term uncertainty, such as patient's response to a medication, may be alleviated by new information; uncertainty about long term prognosis, such as whether the patient will regain the ability to walk, is untenable, and families may require emotional support when information is cannot be obtained (McCormack, et al., Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach, 2011).

Focused observations

- #25 Procedure ends in P's room. A, R, F trying to get P to wake up, ask P to follow commands. A tells F and R if P doesn't return to baseline neuro status in an hour, get CT. Team discusses meds, and P status trying to figure out why P not very responsive now. A and F ask R if Ortho has consulted on this P recently. R reports date of last consult. F tells R about order to get CT if P still unresponsive in an hour. A orders meds, because team thinks P has a resp. infection. CM talks to NP about family situation. Son is in military and needs leave, or he will go AWOL. . . . R tells story of another P to illustrate meds needs of this P. BN asks if oxygen levels should be turned down.
- ** #21 BN tells R that P is requesting to eat. R questions whether P has been eating well so far. Team wonders if P needs tube, if plan is to take out tube tomorrow. R asks F. F says, yes, gives order to remove tube and give P food. BN reports order to R, who puts it in chart. BN requests that R change medication delivery mode for P in chart. NP asks why team is ceasing tube feeds. BN explains. NP tells R to consult with nutrition.

Contingencies. When course of care is uncertain, or patient responses to a particular treatment are known to vary, contingency plans are an absolute requirement, providing a ready answer to predicted uncertainties. In the BICU, contingency plans are the norm rather than the exception. Contingencies are a way of establishing consensus in spite of uncertainty; when a specific course of care cannot be determined, contingency plans limit decision making to a well-defined set of alternatives.

Focused observations

- #28 A reports results of procedure to R. Now that swelling has gone down, A doesn't think there will be a problem. A will tell non burn staff R that does airways to check on P-P should sit up overnight. F expresses worry about airway
- #29 F reminds R to check P in 30 mins. A gives contingency order--meds may need to be adjusted if P needs more support (becomes hypotensive). If this happens, then switch meds and stop diuretic. F tells R don't switch meds and stop diuretic all at once. Stagger this, so that team can determine which helped. A thinks problem with P's neuro status is related to sedation because of A's exam of neuro status. A educates R and F about a procedure.

Lather, rinse, repeat. While establishing consensus is the primary aim of morning and afternoon physician rounds, consensus gaining is an iterative process that occurs continuously throughout the day; a cycle of information sharing, collaboration, addressing uncertainty, decision making, contingency planning, and plan testing occurs in response to newly acquired information, patient responses to treatment, or other new symptoms or developments in the patient's condition.

Focused observations

- #23 NP consults with Pharm on phone about P's antibiotics, discusses options including double coverage. Confirms double coverage standard, reports this to R. A confirms order in chart, but wonders if another antibiotic is better. A calls Pharm again, gets new info, changes meds order with NP.
- #24 A gets call again from Pharm, single coverage is actually okay. A adjusts antibiotic order again.

Priorities in information and planning

In the context of the stages of patient progress derived from general observations, time frames for expectations and planning were an object of specific interest. As a potential source of conflict, a significant trend in physician communication was the prevalence of short term expectation setting and planning, such as daily care updates, and a relative absence of long term planning; little discussion involved future expectations of patient progress, enduring limitations to function, or preparations for disposition. In contrast, family questions to clinicians or discussion within the family more frequently centered around long term plans and goals. Long term versus short term planning and expectations are discussed in further detail in family and patient interviews.

Ships passing: Clinician-family incongruence in time and space

With the aim of targeting potential barriers to effective physician-family communication, structural incongruences were noted between family and physician availability and presence. First, a formalized dis-chronicity exists between clinician and family time spent with the patient: physicians visit the patients before and during morning rounds, from 8:00-9:00 a.m. Family visiting hours do not begin until 9:00 a.m., at which time the physicians are generally absent from the BICU, or are engaged in collaboration or social discussion on the floor. Families who wish to ask questions of physicians may be unable to locate them, or may perceive the physicians as unavailable and refrain from interrupting ongoing conversations. While family members may ask questions of available nursing staff, nurses are

not always empowered to provide the kinds of information requested by the family. Lack of physician availability is discussed further in family interview results.

Attempts to identify locations associated with effective physician-family critical care communication were unsuccessful. Visiting families congregate either in patient rooms or in one of two waiting rooms; residents localize in a central resource area of the BICU, and remain busy in research or collaboration. Senior physicians are generally absent from the BICU, working from external offices except during rounds. With an absence of shared space, there is little opportunity for patients to speak with physicians in passing. Physicians plan certain communication events with the family, as when family decision making is required (often due to a severe decline in the patient's condition), or when the physician must notify the family of a patient's death. Both instances necessitate planful, considerate communication, and would ideally occur in a private, neutral location. However, there is no designated space for communication in the BICU; and families may face difficult news at the patient's bedside, with concerns of the patient overhearing and becoming distressed by the information, or in the waiting room, surrounded by strangers, potentially resulting in constraint of emotional responses and unwillingness to ask relevant questions that may be of a personal nature. Importance of shared space is further addressed in the discussion of potential interventions.

Family Interviews

Family responses to interview questions regarding initial communication, communication that was helpful, and problematic communication were subjected to thematic analysis and salient themes were identified in the context of expectation development among families. Issues of *content* (what was said) and *context* (how it was said) were addressed.

Table 8. Family Interview Themes: Content and Context

	Family Interview Themes: Content and Context		
Type of Communication	Content	Context	
Initial communication	- Too much information	- Family experiencing emotional distress; difficulty focusing attention	
	- Information not specific to patient; too general	- Information provided by clinician unfamiliar with patient condition	
	- Information delayed	- Waited too long to find out information about patient condition	
	- Too little information / information all negative	- Clinician failed to provide significant information, or only provided negative information	
Helpful communication	- Clinician explained/simplified medical concepts	- Clinician perceived family did not understand information presented	
	- Clinician initiated communication / provided information about patient	- Routine phone calls or in-person updates (by some clinicians)	
Problems in communication	- Clinician could not answer question	 Specified another physician (i.e. attending) would have to answer Specified complexity / difficulty answering question 	
	- Clinician displayed condescending or indifferent attitude	- Disregarded or did not take family question / comment seriously	
	- Clinician provided information irrelevant to family member	- Failed to provide information relevant to family regarding long term expectations/planning	
	- Clinicians or staff members provided conflicting information	Lack of standardization in family protocols (visitation, etc.) Unsynchronized information (clinician provided information that another clinician was unaware of)	
	- Clinician did not initiate contact / seemed busy / unapproachable	- Unable to speak with physician to get needed information - Not updated and unable to obtain information when absent from the BICU	

The most commonly cited problems among families were related to information; 13 out of 20 reported that they were unable to obtain needed information, that they did not receive information in a timely manner, or that they only received information upon request, and 8 out of 20 reported difficulty obtaining information due to absence from the BICU (Cristina Farkas for SEE Project, 2012-13). Completeness of information received has been demonstrated to be significantly linked to family satisfaction (Heyland, et al., 2002).

The following table lists examples of family quotes identifying communication themes; including the content and character of the initial clinician-family communication event, aspects or instances of clinician communication that was deemed helpful, and perceived obstacles to effective communication between clinicians and families. Communication that was initiated by clinicians, and in which clinicians explained or simplified medical information, was deemed as helpful. Problems identified by families regarding information included information that was not specific to the patient and information that focused only on the negative aspects of the patient's condition. Problems identified by families that were specific to clinician and staff behaviors included refusal to answer family questions and demonstration of indifferent or condescending attitudes.

Table 9.	Family-identified	communication	problems

Table 9. Family-identified communication p Example type	Family quote
Initial communication	
- Information delayed/wait too long	I've been here 2 hours Two-and-a-half hours you know I asked his nurse if I could see the doctor who saw him and he told me that actually it was the nurse practitioner who had seen him in hydrotherapy so I'm waiting on the nurse practitioner.
- Family in emotional distress	Um, it's a very emotional time to spend so much time, whether, there are people sleeping in the waiting area and, and I get so little sleep, and then you're on edge because you, you're family member is so, uh, ill and struggling and it's so hard to see them go through that and um the team also has to understand that to a family this is the one person that's there and nobody else is there to your family, all you see is your loved one in the bed
- Information not specific to patient	And then so looking back on that if you can't, if you can't tell the family any more than just, this is very serious, your daughter if she makes it could be in here 3 weeks to 3 months and then you can't answer any questions, then don't say anything
- Information overly negative	don't be the bearer of bad news if you can't explain it. Say something positive about your unit, that being in the ICU we're able to provide a much more sterile environment, we're able to provide a more one on one care, Say things that are positive about what your care is gonna be able to provide for your loved one, not something like what we were told because then that just set up a mindset of kinda likedon't be death and doom you know if you can't back it up
Helpful communication - Clinician explained medical concepts	and um, she basically very, very completely explained to me, um, in, in terms that were very easy to understand what my father's injuries were, what the extent of his injuries are and heals
- Clinician initiated communication	she took it upon herself at the end of her shifts early in the morning to call me and just give me an update on how my dad's night was, which was incredible, she was wonderfulIt, it was a brief phone call. It was just a brief phone call to say, hey [Name], I just wanna let you know your dad had a great night. Um, you know there was a minute that his, his uh, respirator came off of his trach and we got it right back on though and you know no troubles from there, she sa-, he rested well, you know he, he had a really great night. So just for her to call and have that little thirty second you know let me know how everything went was really wonderful
Problematic communication	
- Clinician attitude – rude / indifferent	my father has a history of drinking and they told me that they felt like he was having um, detoxification symptoms and I asked, you know how long does that last? And she was, well we can't give you a time frame on that. I'm like, you can't tell me how long the body naturally takes to process detoxing and finally I was like, walk away from me cause I'm getting so aggravated trying to explain something so simple to you and you can't tell me something I can Google on the internetshe was a bit condescendingif I don't know the answer and I say it really nicely it's one thing, but to act like you're bothering me is another
- Clinician could not answer – family referred to other (absent) clinician	Oh no, [NP] couldn't answer anything because I asked herand [NP] couldn't answer anything because [NP] was just a nurse practitionerAnd in my mind, what that did for me was then that set up an impression of the nurse practitioner was that the nurse practitioner would deliver some news, whether good or bad, but I sure couldn't ask any questions because then I would quickly be told, well you're gonna have to ask the physician about that, the attending about thatthen we were left hanging and there wasn't anyone there, the attending was not there to answer questions at that time
- Clinician is unapproachable – possible consequences for communication	I have a fear of reprisal, if you speak against someone who is in a position to care for your loved one, they may treat your loved one differently and I don't want to jeopardize my dad's care because I've ticked somebody off or offended them you know?
- Clinician provides contradictory information	Somebody yelled at [family member's] son the other night too at the nurse's stationI was walking past the nurse's station with [family member's] 12-year-old son to go back and say goodnight, she said, you guys can't go back there it's after visiting hours, you got to leave. I said, I thought visiting hours ended at nine. She look at the clock, it's 8:10, she goes, I'll, I'll check. She walked off and she said, one of you can go back, the other one's gotta stay here

Alternate sources of family expectations

In addition to physician communication, families reported prior experience (i.e., work in the health care field, or experience as a hospitalized patient), religious faith, and personal knowledge of the patient as means for developing expectations about the patient's condition and potential for recovery.

Table 10. Alternate Sources of Family Expectations

Developing expectations	Family quote
Religious faith	
	and absolutely religion you know yeah our faith is what's got us to this point as far as I'm concerned. I mean it really isOur belief, belief in God and knowing that he is the you know the healer and it's only through him that anything is. I mean that's what we believeand I mean I know the doctors and the nurses are very smart people but they only do what you know they, they know what they know and can do what they do you know through him and our faith, our belief, and you know just prayers of everybody is what's helped us.
Prior experience	
	I look at all of his machines. I look at his blood pressuretemperatureheart rateO2 saturation, and then I look at his respiratory machine andthe settings on it, I actually have an understanding of the respiratory settingsI look at his medications, what he's receiving and Ihave a very good understanding of medical equipment and what to look for.
Personal knowledge	
	I'm very used totrying to understanding someone and their body language without them talking to me, or being able to verbalize andso you know I look at a lot of things like if he's smiling, if he's just kinda, um, whatever, you know? Those are things that I look at on, on his progressWell, he's my daddy, I've looked at him for thirty one years! I know his expressions, I know so muchhe couldn't say anything, but I could tell by his smile and look in his eyes [what] he was sayingand he was shaking his head, nodding yes, so

Expectations: Dual Coding of Family and Clinician Interviews

Formulating expectations

Family and clinician statements related to forming expectations were coded according to the dual process of decision-making, based on the understanding that individuals' expectations are implicit in their decision-making processes (Henderson & Chien, 2007). Clinician statements that served to formulate expectations individually for the clinician, collaboratively among clinicians, or that discussed plans of communicating expectations to the family, was coded as either *reflective* (*C-system*) or *reflexive* (*X-*

system). Family statements related to expectation development included discussion of communication by clinicians, responses related to their personal assessments of the patient's condition, and other factors that they expressed as directly related to developing expectations about their own roles in the BICU, the patient's condition and prognosis, clinician duties and obligations.

Families rely heavily on the X-system for identifying patient needs based on facial expressions or nonverbal behaviors; interacting with family members / enacting family dynamics; conforming to clinicians expectations; evaluating clinician response to patients; and hypothesis confirming (as in, reifying media representations of physicians, even when they run counter to direct experience). Family use of the C-system is not readily apparent in the critical care context, except in the case disconfirming attribution biases. This takes the form of excusing or justifying undesirable clinician behavior and communication: frequently when families reported dissatisfaction with clinician communication, they

"and then I also look at whether they have inhalational injury or not because inhalational injury can definitely cause a lot more issues because they have prolonged ventilatory needs... They're at high risk for pneumonias and ARDS and all of that. So those are kind of just the bare minimum things that I look at as soon as someone says we've got a new patient coming in. And then from there I just look at their comorbidities, you know, do they smoke, do they have heart disease, diabetes, things of that nature, things that we, we always look at as physician as things that are risk factors for various complications. And then I use that to kind of gauge, you know, what are their risks? Do they have a risk for not being able to come off the ventilator because they're [a] smoker who has severe COPD and just having that breathing tube in is a risk factor for not being able to come off the ventilator?

concurrently justified or excused undesirable clinician behavior, citing clinicians busy schedules, excess of patients, and career pressure.

Overall, clinicians use C-style to a much greater extent than families do. Clinicians use C-system when diagnosing, prognosticating, providing routine care, following communication protocols, teaching, and rule-following. The following is an example of developing expectations in terms of problem-solving for the purpose of prognosis and patient care.

Clinicians recruit the X-system for tasks that require use of generalizations (including stereotypes) about patients, empathizing, perspective taking, responding to patient or family emotions or expressions, learning social norms of team behavior, and enacting team dynamics. In this example, an attending describes responding to her perception of a family members misunderstanding.

"...when they're privy to a conversation that is purely medical lingo and you can, you just, you can see it in their face. They're, I mean they just kind of gloss over, they have no idea what you're talking about, or they just kind of pick up on random little terms. And they're like what does that mean and you can just tell that they don't understand. So then you go back and you say, "So I know that was a lot of medical lingo. Essentially what we said was this. And this is what it means for your family member, and this is what we plan on doing about it."

In addition, families reported a style of expectation development that did not correspondly precisely to either X-system or S-system processes. In rounds, when discussing decision processes, physicians typically spoke of decision-making in propositional terms which is typical of controlled, reflective C-system processing: "if the tests confirms X, then we will do Y." However, in interviews, physicians revealed that much of their decision-making takes on a more gestalt approach. This type of cognition follows the form of automatic thinking, in that knowledge seems to come from an implicit "knowing" rather than an explicit reasoning process. One physician described it this way:

"... I get the sense and I'm learning this very quickly that as a new attending you learn very quickly with repetition and experience and just knowing. And that's why, you know, when I look at my mentors and the people who taught me, I go how do they know? And it's just because they've been doing it for 20 years and they just know. It's just an experiential thing. And so, you know, in the burn unit you just kind of get a sense of I mean there's, there's obviously literature to support a lot of the decision making that you have. But there's also kind of just an overall gestalt where you say well it's a 20% burn in a patient who's fairly young will probably do fairly well..."

The process described by the physician has characteristics of both C-system and X-system; it is an integration of medical knowledge that has become automatic. Automaticity is commonly developed in areas of expertise (Dehn, 2008).

Descriptive Statistics

Ten clinicians were interviewed; including five attending physicians (3 female, 2 male); 2 bedside nurses (female); 2 bedside/charge nurses (female); 1 charge nurse (female). Four of the ten clinicians were aged 18-34, and six were aged 35-64. Twenty family members were interviewed including 6 daughters, 5 wives, 3 mothers, 3 fathers, 2 unmarried partners, and 1 son; five of these were ages 18-34, thirteen were ages 35-64, two were age 65 or over; four were local residents and sixteen were from out of town. Twenty patients were represented. All had been admitted to the BICU and 19 had a length of stay greater than or equal to five days; one had a length of stay less than five days. Three patients died while in the hospital; 17 were discharged.

Qualitative Analysis: Salience is Golden

In the thematic analysis of the observation and interview data, salience, rather than frequency, of themes was the standard for identifying the primary factors related to expectations. This approach was required, as frequency of codes did not provide a nuanced understanding of the data collected. As such, quantitative analysis was both impractical and insufficient for defending a theoretical understanding of critical care communication and intervention design; qualitative analysis was preferred in the context of a theoretical approach. Salience has been established in the literature of patient-centered communication as a key criterion for identifying significant elements of communication (McCormack, et al., Measuring patient-centered communication in cancer care: A literature review and the development of a systematic

approach, 2011). General observation data was evaluated and a grounded theory approach was used to identify themes from the general observations to inform the collection of focused observation data.

Focused observation data was evaluated for the purpose of this study (thesis) to identify themes for characterizing communication-as-usual and communication problems. While the data was discretely coded and is suitable for quantitative analysis, its scope is decidedly narrow in relation to the theoretical aim of this study. The data collected is site-specific, time-bound, and widely variable due to changes in patient volume and staff rotation (including the resignation of the senior attending / site leader, a period of variable interim leadership, and finally institution of a new site director), which necessarily influence social structure and interpersonal interactions within the unit.

Clinician and family interview data was evaluated subjected to thematic analysis using a grounded theory approach. Themes surrounding communication were identified, including the quality and content of first clinician-family communication, clinician communication deemed as helpful by families, communication problems identified by both clinicians and families, and clinician reports of the process of expectation development regarding patients. Clinician and family interviews were evaluated in the context of a dual-process model of social cognition, in order to demonstrate relative variance in reliance on different cognitive systems in a between- and within- subjects design (clinicians vs. non-clinicians—and clinician differences by specialty—primarily physician vs. non-physician)—as correlaries, differences in recruitment of brain regions may be inferred based on neuroeconomic principles and evidence. However, as this is an entirely new application of the dual-system model, construct validity of the dual-process variables has not been sufficiently established for the purpose of quantitative analysis. Establishment of construct validity is intended as a line of future research, however it was deemed an impractical pursuit within the confines of this study. Thus, a thematic analysis is both sufficient and appropriate.

Interpretations of Results

Systems integration, meet program evaluation: People, Process, Policy ⁷

General observations revealed senior physicians—the attending and the critical care director—as key players in formulating expectations for the behavior of other clinicians through a hierarchical model of enculturation. As such, messages about how to communicate patients are constantly being reinforced; behaviors that may seem innate or natural to the clinicians themselves are actually the product of the culture of medicine. Because cultural transmission is so tightly woven into the healthcare culture, for an intervention to be effective it must rely on a "when you can't beat 'em, join 'em" approach. Senior level clinicians—primarily attendings—are thus the ideal targets of any behavioral, or communication, intervention. General observations also brought to light physician rounds as an efficient process for incorporating families into the healthcare team without disrupting the rhythm of the unit, or placing any additional care duties (or bureaucratic burden) on already heavy laden health care providers.

Focused observations served to circumscribe the shifting roles of patients, clinicians, and families over the course of care in the BICU, and elucidated the prominence of cultural transmission (enculturation) in shaping clinicians expectations about their own role in the healthcare culture, including expectations about patient care and about communication with families.

Implementing and reinforcing positive family roles—by identifying families as critical members of the healthcare team, with specific goals and responsibilities throughout the care process—may be viewed as a *policy* of role-making for the family. Family role-making occurs within the same context as clinician role-making, via hierarchical enculturation. As professionals in the care process, all clinicians can participate in family role-making—and they *will*, by default of enculturation process.

Family and clinician interviews highlighted the differences between where the root of the communication problem is perceived to lie. Interviews also brought to light the distinctions in how

⁷ The three crucial elements of systems integration theory are people, process, and technology. Because my approach relies on principles from both program evaluation and and systems integration perspectives, *policy* is a better fit for a third variable.

expectations are formed by clinicians and by families—pointing to disparate decision-making strategies, and perhaps providing a brain-based explanation for clinician-family conflicts (or communication crises) that so frequently occur at points of decision.

In sum, the results have provided us with the key cornerstones for building an immediately accessible, socially smart, brain-aware intervention, with a self-perpetuating mechanism of social acquisition built in, capable of leading us toward a forward-thinking, economically sustainable non-intervention approach to the family-centered future of healthcare.

CHAPTER V

BACKGROUND: EVOLUTION OF A COMMUNICATION INTERVENTION

Purpose

The purpose of this chapter is to outline the trajectory of the research project in order to provide a nuanced understanding of the conceptual perspective that is presented, and to demonstrate the aptitude of a transdisciplinary approach. Adaptation of the research question in response to ongoing data collection and shifting of the focus of the research strategy will be addressed.

"Seek not to know the answers, but rather to understand the questions..." – Kung Fu^8

Introduction

The answer to any research problem is necessarily contingent upon the question presented. In the case of intervention research, designing an effective intervention requires that we have an accurate understanding of the problem that needs to be addressed—in essence, that we formulated the research question in such a way that an appropriate answer can be obtained.

Intervention literature is rife with solutions to communication problems; and healthcare delivery is replete with problems in communication. In the interest of efficiency in the research process, care should be taken to evaluate and refine research questions to deliver astute solutions. This study incorporates research questions that are aimed at a refined understanding of the problem (communication crises), the solution (communication intervention), and the problem solving (intervention research).

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⁸ Donigar, W. (Director), Spielman, E. (Writer-Creator) & Zweibac, A. M. (Writer), 1973. The Tide [Television series episode]. In J. Thorpe (Producer), *Kung Fu*. New York: American Broadcasting Company.

Evaluating how we are conceptualizing communication problems, and what intervention research is really telling us, will allow us to develop communication intervention designs that are both versatile and evidence-based; that are more efficient than standard intervention research practices; and most importantly, that have predictive value.

Evolution

The crisis meeting

The status quo in the BICU is that ethicists are called in to arbitrate when a conflict in communication between clinicians and family members has occurred. The standard term for this intervention is an ethics consult; however, it is referred to in the BICU as a "crisis meeting." The ethicist role is immediate and brief; the intention is to come in and "fix the crisis" so that doctors can go on with doctoring. This strategy is valuable, but because expectation management does not occur until negative expectations have already been developed, the crisis intervention often cannot compensate completely for the negative experience of interpersonal conflict between the family and clinician.

The family meeting

The basis for this approach is the assumption that physician-family conflicts arise due to a failure of consensus regarding expectations for the patient. When expectations are misaligned, as when patient outcomes are much worse than expected, families may have difficulty trusting the physician or accepting the reality of the patient's condition. Families may also have unformed expectations about the care process, the severity of burn wounds, the length of course of recovery, and their roles in relation to the patient. When specific expectations do not exist, everything can come as a surprise. The goal of the family meeting is to "fix the family" by providing enough structure in terms of expectations so that they are not surprised, and to help shape family members as avid participants in their patient's care process. The role of ethicist is shifted from arbitrator to mediator. By identifying issues that lead to mismatched

expectations, families can be prepared early in the care process for the events the lie ahead in burn treatment and recovery.

Family-centered intervention suite

Physicians advised of the difficulty, inconvenience, and relative non-utility of giving families too much information in an initial meeting. Burn wounds are complex, and require a long time to heal, and patients go through several stages on the way to recovery. An intervention suite would consist of several planned conversations throughout the course of care regarding patient progress, milestones, and future planning, with the ethicist assuming the role of family educator. One drawback to implementing this approach in the BICU is that patient progress is often unpredictable—patients may get worse before they get better, need unexpected surgeries, or face unanticipated complications—so without an ethicist on site full time, family communication would suffer.

Communication training

The perceived inability of ethicists to be available and informed in order to communicate with families about clinical issues several times throughout the patient's stay presents a challenge; if the ethicist was not apprised of the full situation, how could they be helpful? Communication training shifts the ethicist role to communication coach, in which they would instruct clinicians regarding problematic communication styles and behaviors, and the need for earlier and increased frequency patient contact. In this model, the responsibility of family centered care is shifted to the clinicians; the burden of family emotional care rests with the same providers who carry the burden of patient medical care. Attempts to retrain clinicians' communication habits may face limited success, as training sessions of a communication intervention suite designed to teach nurses to deal with communication problems improved which focused on awareness, emotions, listening, and problem-solving increased measures of self-efficacy in these areas but did not improve performance (Doyle, Copeland, Bush, Stein, & Thompson, 2011).

Tools & technology

Preliminary observations and review of family-centered literature resulted in an increased understanding of family communication needs. A number of tools were suggested to assist with compliance in implementation of the intervention. Updated intake sheets could better represent family centered issues by specifying primary contacts and whether these were the same as primary decision makers, and indicating the existence of a living will or Do Not Resuscitate order. In congress with the shift to non-paper based information sharing, integration of family-centered principles into the electronic medical records system could provide opportunities for accountability. Patient medical records consist of templates including medical history; current condition, including pain, symptoms, physical assessments, and diagnoses; physician orders for medication, lab tests, radiology, or diagnostic monitoring; and lab, radiology, or other diagnostic results; and physician and nurse notes. All of these templates occur in two "panels"—one for physicians and one for nurses—with varying access to each template (i.e., nurses can view physician orders but not change them or input new information). Suggestion for development of a unique "family" template to incorporate information about primary contacts, notes about communication with families and family dynamics, and fields to record daily contact with families including questions that need to be answered, procedures requiring consent, and updates about patient milestones (surgery scheduled, independence from ventilator, etc). Information sharing is a concern with both paper-based and electronic methods, however, since physicians tend not to review nurse's notes. Whiteboards in a patient's room represent a shared space for information exchange and could be tailored to promote family-centered principles. Drawbacks to the white board approach include concerns for privacy, reports that current whiteboards are not updated consistently, and inability of family members who cannot be present to obtain information.

Integrated Family Communication Protocol (IFCP): A Rolemaking Narrative

For the purpose of this thesis, a narrative training intervention was produced by integrating salient concepts from family based literature and from our observation data, and combining components from various communication interventions to produce a multifaceted evidence-based model that was adaptable to the needs of different units. A narrative structure was used to provide a context for clinicians for integrating family-centered concepts; rather than delineating communication principles, a narrative is produced that follows a typical patient's progression through different stages of recovery, highlighting the most salient family communication needs at different time points, and providing models for integration of key concepts. Role making is the central concept of the narrative; the hierarchical structure of cultural transmission is exploited and families are integrated into the healthcare "team" as recipients of expectation shaping via enculturation.

Themes from the literature and used these themes as a framework for constructing an intervention. Themes from the data serve as a basis for evaluating the intervention, to determine goodness of fit and predict appropriateness (or, likely success) of the intervention. This serves the function of "market testing" the intervention; it should be a useful tool for encouraging buy-in from clinicians, as it will provide evidence that 1) an intervention is necessary (communication problems exist in the unit), 2) family-centered communication interventions have been successful at addressing similar problems in other units, and 3) this intervention addresses the problems identified in this unit. An iterative process of thematic analysis can be used to modify the intervention to target specific unit needs.

The IFCP will incorporate aspects of person (role-champion), process, and policy. Clinicians are entrained in process of family centered communication via a model of rolemaking (enculturation). In this context, family centered communication can be defined as communication that addresses the problems, our sources of dissatisfaction with care, that families report—first, in the literature on family centered adult critical care, and second, in the family semi-structured interviews. While family interview responses

are the primary data I am analyzing, I will also reference data from general observations, focused observations, and clinician interviews to support my claims.

Integrated Family Communication Protocol (IFCP): A Narrative Rolemaking Intervention

<u>Overview</u>. Literature supporting patient-centered communication interventions in adult critical care was reviewed and thematic analysis was employed. Themes were identified from the literature in two primary areas: family reports of dissatisfaction with clinician communication, and patient centered communication interventions that improved family satisfaction.

These themes were used to structure a family-centered communication intervention (IFCP) to be implemented in the Vanderbilt Regional Burn Center (VRBC), the Vanderbilt Neurology Intensive Care Unit, and the Vanderbilt Cardiac Surgery Intensive Care Unit.

Measures. Data was collected at the VRBC including general observations of patient care activity, focused observations of physician and interdisciplinary rounds, and semi-structured interviews with clinicians and families. Thematic analysis was applied and the themes were identified from VRBC data in three areas: communication problems identified by the investigator, communication problems identified by the clinician, communication problems identified by the patient. These themes will be used to assess the appropriateness of implementing the IFCP in the VRBC, with priority given first to communication problems identified by the family, and second to communication problems identified by clinicians.

<u>Outcome analysis</u>. Correlation between themes addressed by the IFCP and themes identified in family interviews will serve as a predictor of family satisfaction with the intervention. Correlation between themes addressed by the IFCP and themes identified by the clinician will serve as a predictor of clinician "buy in"—a construct consisting of clinician satisfaction with the proposed intervention and the likelihood that clinicians will voluntarily sustain implementation.

Themes from the literature:

- Increase physician contact with patient (early and often)
- Get information to patient sooner
- First contact should be sooner
- Information should be complete
- Patients want to know more than doctors tell them
- Patients want to know more than doctors think they do
- Nurses are doing a better job communicating than doctors
- Patients want to know more about the future (less about day to day)
- Clinicians communicate more about day to day (from focused observations)
- Incorporation of family into rounds
- Clinician should initiate contact, not expect patient questions (patients don't know what they
 don't know, don't feel comfortable approaching physicians)
- Clinician should be *responsive* to patient needs, communication style, etc.

Family Integrated Communication Protocol

Introduction. Ethics team will participate in role-making for the clinician; ethicists will introduce the IFCP

to both physicians and nurse practioners. Since attendings and nurse practioners play a key role in implementation, ethicists will provide extended training (use of SIM Lab is recommended).

In delivering the intervention, clinicians (both physicians and NPs) will participate in role-making for families informally, through a series of guided conversations that occur throughout the course of care. NPs will more engage in role-making for other clinicians and care providers (bedside nurse, caseworker, physical therapist, etc) both actively, and via cultural transmission, by facilitating family involvement during rounds guiding provider communication in rounds to be more family-centered.

The purpose of the protocol is to help families be prepared for what to expect once a patient has been admitted to the burn unit. Assymetrical information leads to asymmetrical expectations.

Clinicians roles include helping to manage expectations for the family about the patient's future course of care, but also expections about the family's role in that care.

1) Families need orientation (resuscitation phase). Families ending up in the VRBC waiting room might as well have been dropped into an unknown jungle without a map or a compass. They do not know what to expect in terms of what might happen to the patient, what their roles are concerning the patient, or even how to navigate their environment to meet basic needs (where to eat, sleep).

Clinicians, on the other hand, navigate this rough terrain everyday. Clinicians need to guide families by first orienting them to their surroundings--letting them know where to find the resources they will need, and who will be their guide.

<u>Orientation</u> (resuscitation phase): During the initial 24-72 hour period after a patient is admitted into the burn unit, clinicians will be working to resuscitate the patient. During this phase it is typically unclear whether the patient will survive.

Clinician role. It is important to let the family know that the doctors are doing everything they can to ensure that the patient survives, but that it is too soon to determine the likelihood of survival. Let the family know that it may be some time before they hear anything, but that the doctor will speak to them as soon as the patient's status is stable. Ideal solution: attending will speak to family within the first 3 hours following admission. Workaround solution: NP will speak to family within the first three hours following admission.

Clinicians may be unwilling to broach the subject of patient survival with family members, for fear that, if the patient survives, they will have caused unnecessary distress to the family. However, family members do not respond negatively when the outcome is better than expected; in fact, positive surprises often result in increased confidence in the level of care the patient is receiving, and being told to expect the worst was perceived as transparency of communication on the part of the clinician. In the reverse scenario though, when the prognosis is poorer than expected—and even more so when a patient who was expected to survive dies—family members tend to blame clinicians, interpreting this as a lack of transparence in communication.

Family role. During this time the family can provide helpful information about the patient such as medications or other drugs the patient normally takes or has taken recently; lifestyle factors like smoking habits or alcohol consumption that could influence the patients care; and contact information of the person who is authorized to make medical decisions for the patient (next of kin or power of

attorney).

2) Families need parameters (rehabilitation phase). During the first week to ten days following resuscitation, clinicians will be assessing the extent of the burns, as well as damage to the lungs. Though the patient is stable, and their chances of survival are increased, there is still a great deal of uncertainty. Infection presents a risk at this stage, damage to internal organs becomes more apparent, and ventilation is not always straightforward.

Clinician role: how bad could it be? Families should be informed of all new developments in a timely manner, but it is not enough to tell the family that the patient has a lung infection, kidney failure, or brain damage—medical findings must be put in a context that the patient can readily comprehend. For most families, the two most important questions to address are survival and function. If at any point things take a turn for the worse and survival is in question, or it becomes clear that the patient will not regain consciousness, it is best to tell the family right away. Similarly, if it is clear that a patient will lose a limb, require a wheelchair, or be unable to work in their previous profession, the family should be notified right away. Ideal solution: Families will attend rounds (either physician rounds or interdisciplinary rounds); attending (in physician rounds) or NP (in interdisciplinary rounds) will address the family to "interpret" medical information and solicit questions. Workaround solution: NP will address the family in person at another time during the day when they are available (see whiteboard), or will contact them by phone to provide a daily functional status update.

Clinicians often choose to delay bad news, for a variety of reasons (cite focused observations). They may be trying to assess the family's emotional state, waiting for another family member to arrive to provide support, waiting on tests that will demonstrate that their observations are correct, or simply avoiding the unpleasantness of such a conversation. However, families continually cite withheld or delayed information as a primary source of dissatisfaction with provider communication (cite research, cite interviews).

Many clinicians assume that if the family has questions, they will ask (cite physician interviews). However, family members cite difficulties with initiating communication, such as inability to formulate appropriate questions (cite family interviews), or perception that the clinician is too busy (cite family interview). Clinicians can best help patients formulate expectations by taking an active approach—telling the patient what is important, and asking if they have questions or concerns. Clinician time spent listening to patients is consistently related to family satisfaction with patient care (cite literature).

Clinicians often cite difficulty with explaining the complexities of burn trauma and burn care in a way that patients can understand (cite clinician interviews), and this asymmetry of information is to be expected considering the degree of disparity in levels of education and experience.

One way clinicians can address families concerns is to talk about function rather than pathology: for instance, rather than discussing only the extent of lung damage, the clinician should provide a context for what this could mean for the patient and family in everyday life—the patient may require breathing assistance for the rest of their life.

Family-role: Families can improve patient care by being involved. Attending the physician rounds is the best way to keep up with what is going on with the patient on a daily basis. Although the physician's time during rounds is limited, this is the appropriate time for families to ask questions or voice any concerns about the patient.

Families who remain with the patient throughout the day can help monitor the patient's condition, looking for indications of pain, level of arousal, mood, or difficulty breathing, and provide feedback to clinicians. These subjective reports, in addition to routine monitoring and examination, can enrich clinician's understanding of the patient's condition, and in some cases help to guide difficult care decision (cite focused observations from bedside nurse, the patient seemed to be struggling, family observations).

3) Families need direction (~10 days to several months - recovery phase). Clinicians can provide direction for families by letting them know not just how things are right now, but what likely lies ahead. Families reported that the type of information they received from clinicians tended to be short term, and unlike clinicians, families were unable to translate daily information into long term expectations (cite family interviews).

Clinicians tend to focus on the here and now, such as pain levels, blood pressure, and O2 stats (cite focused observations, general observations codes); however, the questions families want answered are more future oriented: will the patient survive? How long will they be hospitalized? What function will they regain? Will they be able to walk, talk, work? What am I going to need to do to help them? How am I supposed to plan?

<u>Direction:</u> While clinicians cannot predict the future, they are certainly more experienced than family members when it comes to understanding the potential outcomes at any given time, in consideration of each patient's changing condition.

Clinician role. Clinicians should guide families understanding of how changes in daily condition impact future course of care, with particular emphasis on significant deficits of function that would require family support, from practical care needs such as help dressing or bathing, to financial concerns that may arise if the patient is unable to return to work. Ideal solution: Patient will attend interdisciplinary rounds; NP will provide information related to medical condition and continued care; social worker, physical therapist, (other?) will address respective issues. Workaround solution: NP will communication information from rounds regarding medical status update, as well as interdisciplinary concerns, at another time during the day when the family is available (see whiteboard), or by phone if the family is unavailable. Note: these issues are most relevant during the patient's time in the stepdown unit. Many of these issues do not change from day to day, thus the clinician should structure communication around any changes in function or future course of care. Examples: patient will continue physical therapy daily until they are able to walk again, patient will continue occupational therapy until they are able to feed themselves.

Family role. During this phase, families can assist with providing practical care to the patient, such as help feeding, bathing, toileting, and wound care. While these services are routinely provided by the nursing team when families are unavailable, clinicians, families, and patients alike report more positive experiences of care when families are involved (cite literature; cite clinician (nurse saying how families can help - interviews). Families also provide social support that is important for patient morale and can improve the patient's overall experience (cite literature) as well as decrease recovery time (cite literature-earlier disposition).

Notes: in the strictest sense, the phases of resuscitation, recovery, and rehabilitation are neither independent nor mutually exclusive. There is bound to be overlap in terms of patient condition and

course of care, and thus also in terms of clinician roles and family roles. These boundaries are delineated in order to provide clinicians and family members with a common language for discussing the patient's progress, in order to establish greater symmetry of expectations.

4) Families need support (disposition phase). During this phase families and patients are transitioning from a life that has been centered in a hospital room, to either a home environment or an ongoing care facility. Clinicians can educate families in ongoing care (wound dressing, physical rehabilitation, signs of infection, etc.)

<u>Support:</u> If the patient is going home, the transition may involve a shift from relative dependence on the hospital to staff (on the part of both the patient and the family) to family responsibility for the patient's care and wellbeing.

Clinician/provider roles. The NP and members of the interdisciplinary team should take the initiative to provide information from their respective disciplines that family members regarding caring for the patient, as well as coping with new roles and responsibilities. Referral to appropriate resources (family counseling, financial assistance, specialists and primary care providers for patient follow up) are essential for family stability, and should be deemed the responsibility of all providers in accordance with their respective disciplines. For instance, the NP (as well as bedside nurses) should education patients regarding continued wound care; the physical therapist should demonstrate exercises for continued rehabilitation; the social worker should direct the family to resources for financial assistance with medical costs when appropriate.

Family roles. The family should be prepared for challenges in the adjustment period following disposition. Families members must determine division of responsibilities when a patient requires continuing care or financial assistance. Continued social support from family members is essential for optimal patient outcomes.

Analysis: The path of the patient from admission to disposition reflects two things: First, a relative increase in time intervals between family centered communication events; and second, a relative shift in dependence on clinicians along the "hierarchy" (noted in general observations) from 1) the initial phase in which the attending (and to a lesser degree, other physicians) is of primary importance (both in patient care and family contact); 2) the intermediate phases, in which the NP (and to a lesser degree, other members of the nurse team), are of primary importance (again, both in patient care and family contact); and 3) the final phases (of recovery and disposition), where ancillary interdisciplinary team members (social worker, physical therapist, psychologist, occupational therapist) roles become primary in patient and family support.

Ethics in attending

A final adaptation to integrated communication / family rolemaking is to exploit the hierarchic structure of cultural transmission as a means for intervention delivery. In this iteration, ethicist roles shift from outside consultant to integral member of the healthcare team. Roles of Ethics Director and

Attending Ethicist are proposed, mirroring the hospital unit structure. The unifying concept is to endorse clinical ethicist roles as specialists in patient and family issues and advocacy. By integrating ethics at the attending and administrative levels, these ethicist-clinicians are able to influence the structure by means of enculturation. Ethics attendings would have roles parallel to medical and critical care attendings; and presence in rounds would be a primary means of establishing primacy of patient and family advocacy issues.

This approach is recommended to address issues of ongoing adherence to family centered protocols, fragmentation, and continuity of care, as the ethicist becomes primary contact for patient and family and the primary purveyor of family-centered principles. It addresses resource limitations, as clinicians report they do not have time for increased patient contact. It addresses the area of specialization, as it allows clinicians to operate within their area of specialty in providing patient care without diverting cognitive resources to issues of communication, while allowing families and patients access to "specialist" communication and advocacy by ethicists. This approach transitions the role of ethicist as consultant to ethicist as specialist / clinician. Beyond direct interaction with the family, ethicists can collaborate with clinicians to provide in-the-moment corrections and attention to patient and family needs, versus formalized outside training; this allows for cultural transmission of ethical / patient-and family-centered principles. In this sense it is a "non-intervention" in that it is capable of producing long-term systematic change, yet it does not require disruption of current care routines or overt behavioral change on the part of clinicians or families.

CHAPTER VI

CONCLUSIONS AND DISCUSSION

Conclusions about the Problem

Summary of findings

The one true synthesis of all the study's findings is that healthcare is a world fraught with contradictions. The same hierarchical structure that ensures order, efficiency, and personal accountability is also one of the most pervasive tools is also responsible for engendering divisiveness among clinicians and allowing undesirable responsibilities, such as family communication, to be continually shifted to less experienced providers. The system of enculturation that so seamlessly transposes bright young medical students into brilliant diagnosticians also reinforces a culture of depersonalization of patients and condescension or indifference towards families. Meanwhile, it is this depersonalization that allows clinicians to keep doing what they're doing day to day, and it is the lure of the whopping dollar signs that keep medical students and residents going through years of arduous training.

The collaborative process of decision making seen during rounds serves as a safety net for residents, who can test and refine their clinical decisions without having to target practice on unsuspecting patients. The unseemly side of collaboration, though, is that no one person is responsible for a patient's welfare. Ideally, the attending is present whenever a major procedure is performed, and is where the buck stops in terms of liability. But collaborative decision-making, particularly in view of some of the rather non-specific, contingency-ridden decisions that are floated in critical care, also seems to provide an escape route, allowing physicians to likewise float responsibility when decision-making goes awry.

What of this rhythm?

The BICU, like most hospital units, seems to run like clockwork: physicians and nurses moving in and out quickly and purposefully, interacting with patients and machines and each other, exchanging information through conversation and paperwork and computerized records. In one sense, this is the result of standardization practices which began in the 1980s as a mode of quality improvement in medical care (Kinney, 2004). Standardization is associated with improved outcomes, including decreased mortality and morbidity. In other ways, standardization can cause us to overlook systematic processes that may actually be contributing to the problem. For instance, families complained about lack of access to physicians, and physicians complained about family's absence at rounds—however, no one pointed out that the visiting hours for BICU families don't begin until 9 a.m., after rounds are over and physicians have left the unit. A simple structural change of modifying visiting hours to start at 8 a.m. would provide a mutually beneficial solution to both clinician's and families' reported obstacles to communication.

"To those who have, even more shall be given..."

Despite the increase in professional and specialized training by nurses and their increased acquisition of clinical roles that are functionally equivalent to those of physicians, they still remain a socially and professionally separate entity, working in parallel with physicians but not without distinctions. Early in the research process, the SEE team identified nurse practitioners as likely targets for communication training, which would place the burden of patient centered care on mid-level providers who are already carrying the greatest patient load—the choice was made in part *because* the nurse practitioner is currently the only practitioner familiar with all patients in both the BICU and Stepdown, and partly because of feedback from attendings, insisting that they (the attendings) are unable (or unwilling) to take on more family-related duties. The logic behind this decision seems to be that the nurse practitioner should be responsible for families, because she is already responsible for everything else. Suprisingly, despite their overwhelming burden of care, nurse practitioner are willing to take on

new roles as captains of the family-centered care team; they are eager, in fact, for training that may help them to communicate better with families and to derail potential conflicts.

However, just because NPs are willing to take on family-centered responsibilities does not mean they are best suited for this role; in fact, the fact that they are willing to accommodate to family needs and physicians are not is likely at the heart of problem communication with families per se. In a sense, placing the burden of family-centeredness on nurses reinforces the cultural stereotype that draws a distinction between "medical practice" as the domain of physicians, and "caregiving" as the function of nurses. In the BICU, this translates to physicians treating burns, while nurses and allied healthcare providers are treating patients.

Room for error

As an outsider to the world of critical care, observations in the BICU were in many ways unsettling. It is clear that healthcare providers, in addition to their specified duties, take on the additional burden of witnessing patients and families suffering; burn victims experience excruciating pain and often times debilitating functional injury, and the severity of medical complications associated with burns leaves families in a constant state of uncertainty about the patient's survival, wellbeing, and potential for recovery. All of these things made observations in the BICU difficult, however the reality that was the most difficult to assimilate was the clinicians *non-resistance* to uncertainty.

Of course, uncertainty in critical care is a given—life and death hang in the balance. Patients may not survive. Treatments may not work. The doctor may not be able to help. Uncertainty is a tyrant, and resistance is futile. But the ease with which clinicians operate within uncertainty—the acceptance, perhaps even comfort—is antithetical to the patient / family mindset. Patients and families necessarily have a vested interest in the outcome of the care clinicians are providing, and clinicians, by necessity, do not. Observations of collaboration in rounds, discussions over which treatment approach would be more appropriate, often ended with the pseudo-consensus of "We'll do A…or B." As an outsider, and a

sometimes-patient, the idea that my care, my parents care, my children's care—could be consolidated into a medical resident's shrug, and that shrug could have life or death consequences, is mind-blowing.

Clinicians need to remain intimate with uncertainty to be able to effectively do their jobs. Having multiple patients with diverse needs, clinicians don't have the time or emotional reserve to contemplate and deliberate over the weight of each decision in the way that families do; they just have to accept the potential consequences and move on. The disconnect between clinician fluidity and families rigidity of expectations about the patient is substantial, but unavoidable—it renders true empathy on the part of clinicians an illusion, with the most family-centered impulse being to fake it.

Patients are people too...aren't they?

The problem of depersonalization is widely acknowledged in medical literature. Intuitive first year medical students write about the process of depersonalization, and how it is inextricably invaginated in medical education by the dissection of cadavers. Family members in the BICU lamented depersonalizing treatment patients received, and instances of depersonalization documented in our observations were not scarce. One family member who described the clinician's treatment of a patient as depersonalizing described this scenario:

"...my dad's the second door in on the left, everybody that walks by stares at him and I, I just feel like he's had no privacy...he's got you know a [gastronomy tube]...but they could cover that with a sheet...instead of him being embarrassed and feeling so degraded and emasculated, because not only does he have a [gastronomy tube inserted], but there's [feces] in a bag for everybody to see that walks by...when they've came in and checked...his A-line which is in his groin, it exposes his genitals and...you know you can cover him up and do what you need to do, and still maintain some privacy for my dad...if you put yourself in a patient's position, would you want people to be able to see your, your bowel movement or your genitalia?"

The family member, through a process of perspective-taking, describes the experience as embarrassing for her father, but when the investigator questions her, she admits that the experience was humiliating for

her as well. Of note, this particular family member was also a professional health care provider; her experience wasn't one of just discomfort with nudity or a distaste of anatomical processes—her humiliation was specific to her personal relationship with the father. Seeing his exposed genitals and excrement were outside of the normal bounds of an interpersonal relationship; in this way, the experience was depersonalizing for the patient and the family member, even though it may not have been perceived as such by the clinicians.

How about those expectations?

Interestingly, clinician descriptions of how they form expectations about patients provide another perspective of patient-depersonalizing. Physicians commonly refer to heuristics in diagnosing and decision-making. These heuristics streamline the decision-making process, cognitively reducing the complexity of the specific patient by perceptually sorting them into different categories for which an "if-then" proposition exists, indicating a specific course of care.

Patient heuristics seem to come in three flavors: generalizations based on practice experience, statistics from medical research, and rules-of-thumb in the form of if-then propositional logic. Clinicians use generalizing phrases such as "generally, with patients like this...", "when a 90% burn comes in like that", "usually in these kinds of situations" to describe how they went about formulating expectations about, and in turn making treatment decisions for, a particular patient. Statistics and frequencies are reported in the form of, "nine times out of ten, when a patient has these issues, they don't make it." Rule-of-thumb heuristics come from a combination of research and handed-down experience; the Baux score is a first-glance predictor of burn patient mortality that is achieved by adding the patients age to the percentage of the body that is burned. While this certainly makes for a rough estimate, such heuristics do have predictive value and are considered clinically indispensable.

While the use of heuristics improves care delivery by simplifying decision making, it can have negative consequences. Making treatment decisions based on generalizations, rather than the

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¹⁰ Variations of this technique exist that account for inhalation injury and improvements in burn care.

complexities of the specific patient, can lead to physicians overlooking important individual factors in some situations. Even more likely, talking about patients in general terms can sound depersonalizing to families, for whom the patient does not represent a general population, and can lead families to conclude that the physician is not well-apprised of the patient's condition, causing families to lose confidence in physicians treatment recommendations.

Additionally, dramatic differences in family and physician medical literacy and numeracy result in family misinterpretations of clinician communication about the patient. When the physician says that nine out of ten patients like this don't make it, they have an obvious conclusion in mind: "therefore, this patient probably won't make it." For the family member, however, the conclusion is not so obvious. To the family the patient is not the general population; they are not the nine out of ten, they are the *one*—this thinking makes it equally sensible for the family to conclude that the patient will survive—in fact, it makes such conclusions *more* logical than the alternative.

The unexpected

The most interesting finding in this study was, poetically, also the most unexpected.

Observations of physicians collaborative decision-making during rounds, in recursion with shared expectation-making, demonstrates point-of-fact logical, reasoned, stepwise, *explicit*, intentional, *controlled*, C-system thinking. Ask any physician "why" in response to any given treatment, and they will respond with a practiced series of linear propositions that seem to unfold naturally; they verbally draw logical decision trees that seem to imply that anyone, given the same training—the same rules—would come to the same decision. It makes it seem as if the practice of medicine is quite certain, predictable, and not prone to error—yet we know this not to be the case.

What was revealed in interviews with physicians about their decision-making was that a great deal of the actual practice of medicine is not logical, rule based, or explicit. Physicians describe a *gestalt* experience of the patient and their condition, a kind of knowing (or "kind of" knowing), that informs

recommendations for course of care in a way that is less like deliberate decision-making, and more like intuition.

This intuitive practice is, in itself, not problematic; it is often referred to as the "art" of medicine, and is considered a necessary complement to the logic-based "science" of medicine. This raises challenges, however, in the context of expectation-shaping for families. It seems a difficult task for clinicians to be able to formulate expectations for families when they are unaware of how they are forming expectations for themselves. And moreover, defending decision-making based on gestalt, impressionist, "kind of" knowing—versus a formulaic, reasoned, algorithm—is unlikely to convey credibility. And as essential as this "knowing" may seem to the physician's practice of medicine, it is unlikely to instill confidence in families, who may resent the idea of their loved one's care being based on just a "hunch."

Conclusions about the Solution

Enculturation is the predominant form of expectation shaping among health care providers.

Enculturation proceeds in a hierarchical fashion, with communication from highest ranking attending and senior physicians shaping communication beliefs and behaviors of junior physicians and residents.

Physicians and residents transmit formative cultural information to nurse practitioners who enact similar beliefs and behaviors, and translate them to lower level nurses and allied health professionals. Nursing staff are the primary transmitters of cultural information to administrative staff, patients, and family members.

Fix the doctors! The implications of a dominant, pervasive hierarchical enculturation are clear: any long-term, sustainable changes to communication must occur from a top-down level, and all intervention concepts and components will require "buy-in" from senior and attending physicians to be successful. From a systems integration perspective—targeting People, Process, and Policies to affect systematic change—attending physicians are the People with the greatest ability to affect change within

their unit. Moreover, without attending buy-in, no long-term change is sustainable, and intervention efforts are wasted; changes made at lower levels of the healthcare pyramid will be subject to adaptation and overlay by dominant beliefs and behaviors, and thus will in effect be "washed away" by the systematic enculturation process.

The upside of top-down communication: Successful implementation of an intervention would require training only at senior levels. Once buy-in is achieved from the attending physician in a unit—in other words, once the attending is convinced of the problem and committed to the solution—the attending becomes the intervention, and embodying values, beliefs, and behaviors of family centeredness and transmitting entraining these in other providers.

The types of information transferred via the hierarchical enculturation process are identical to the types of information used in formulating expectations *and* in decision-making. This includes information about the patient's condition, family dynamics, medical expertise, decision-making protocols (if-then scenarios). Information about the hierarchy itself is also acquired through enculturation—who's in charge, each caregiver's role, how decisions will be made and how values, beliefs, and expectations will be communicated.

Don't buck the system. In the context of the intervention implementation, you couldn't ask for a more effective and efficient method than enculturation: it allows us to effect widespread change in the system without having to ask the majority of the stakeholders to make any specific changes. Junior physicians, nurses, and other providers need only to keep doing what they are doing—which is, in essence, embodying the values, beliefs, and behaviors that are communicated by their "superiors" within the healthcare hierarchy. Instead, we are simply changing the messages which are communicated to them, and that they will in turn communicate to the more junior levels of the pyramid.

By co-opting the prevailing hierarchical social structure that exists within the medical community, we have secured an incredibly efficient, pervasive, and effective means of cultural transmission (enculturation/indoctrination). This figures into the systems integration model as the *Process* by which the intervention will be implemented. What this means is that few resources are

required for sustainability—attending and senior level physicians will receive initial communication training and ongoing support by the ethics team, which is intended to change the artifacts of communication before they "trickle down" to other levels of the healthcare hierarchy.

Conclusions about the Problem-Solving

Barriers, constraints, difficulties, and limitations in healthcare delivery and communication are, within the U.S. system, nearly universal; and methods of improving communication are widely understood and accepted. There is no controversy over whether physician listening, for example, increases patient/family satisfaction; however, there is disagreement over whether increased listening is feasible within current time constraints, whether increased time with patients adds actual or only perceived value to the healthcare experience, and whether patient/family satisfaction as a goal is worthy of trade-off with financial incentives.

We can assume that communication interventions work; an economic approach to problem solving in healthcare communication does not warrant further concept testing. A synthesis of literature regarding fundamentals of interpersonal communication as an extension of social cognition, and healthcare communication intervention research, makes it clear that healthcare communication *is* communication—functional units of ethical, effective, mutually beneficial communication that are overlooked, undertrained, devalued, or otherwise absent in healthcare delivery result in the disordered, asymmetrical, incongruent, ineffective communication that we understand as conflict and, at its end stage, crisis. Interventions to improve clinician communication by enhancing listening skills; increasing awareness of and responsiveness to emotional states; prioritizing time spent in communication with families; and increased awareness and regulation of clinician attitudes and behaviors that engender family dissatisfaction—any of these will be successful; any of these will improve communication between clinicians and families, and in doing so, any of these will increase family satisfaction.

We can also assume that communication interventions fail: the healthcare system is entropic; continuous intervention contributions over time would be required to sustain any substantial benefit. Communication interventions fail for at least two reasons: changes elicited by the intervention are not supported by the system, and clinician learning of intervention information is not efficient enough to override preexisting automatic behaviors.

What's in it for me?

The practice of medicine is intrinsically rewarding: outcomes are directly related to interventions. Giving the right medicine, at the right time, in the right amount, to the right patient and the response is highly (the not 100%) predictable; getting an unpredicted, undesired response (or adverse effect) is generally accepted as an indicator that *something went wrong*. Even if the medicine sometimes does not achieve the desired result, it's effects fall within a range of relative predictability; responses are fed back into an iterative system of diagnosis and treatment for which possible outcomes are almost always known: if the medicine causes an allergic reaction, treat the reaction, and prescribe an alternative medicine; if the effect is less than desired, increase the dose; if the desired effect is achieved with undesirable side effects, lower the dose, or treat the side effects. Rewards for making the right decision in medicine are direct, and relatively immediate.

Communication with families does not have the same reward elements. It is possible that a clinician could give families all the right information, use language they understand, convey appropriate empathy, and listen intently to their replies...and the family still could leave the encounter dissatisfied. Complexities of emotional stability, belief systems, prior knowledge, and expectations can all lead to responses that seem irrational and unpredictable, and clearly not rewarding. While this is a worst-case scenario, even in the best cases family responses are likely to only be negatively reinforcing, in that the clinician's communication fails to provoke a crises; clinicians do the right thing, and nothing terrible happens. Positive reinforcement from families is rare, but when it does occur it is generally delayed,

nonspecific, and only indirectly related to a specific communication instance, as in a thank you note sent by families after a patient's disposition following a three month hospital stay.

Because intrinsic rewards for communication cannot compete with the immediate, predictable reinforcement of doctoring, it is unlikely that any amount of training would result in communication that is tantamount in effectiveness to medical practice. Likewise, medicine is extrinsically rewarding: insurance companies pay doctors for the medical services they provide, not for how they talk or how the patients/families feel about it.

Supplies are limited

Another reason that communication interventions are doomed to eventual failure (or only marginal success) is that, regardless of how helpful they may seem, they rely on resources that are in short supply. There is only so much time in a day, staffing is at a premium, and providing healthcare is demanding; clinicians must prioritize, and despite all the benefits of family-centered communication, their primary obligation is delivery of care to the patient. Communication training also competes for cognitive resources in an already overburdened system; years of formalized medical or nursing education, combined with sometimes decades of experience in practice, can't simply be undone by a weekend of coaching, or a weekly thirty minute pep talk.

Bigger, smarter, faster

The trouble is that communication training tries to push a boulder uphill; methods that suggest are antithetical to the pervasive, dominant culture. Moreover, they rely on mechanisms of learning that are far less efficient than those of competing messages—intermittent formalized external training of communication protocols is noncompetitive in comparison to a pervasive, continuous, unremitting environment of enculturation.

Train of thought: X vs C system

Think of the brain as the city of New York; cognition can be likened to commuting. The subway system is the preferred method for many; it is the fastest, and because it is relatively expansive, it is useful for travel to most destinations. However, the are some places you simply cannot going using the subway alone, so you may have to combine travel by bus, by car, by ferry, or on foot, and each of these systems travels along different routes and has different "stops" or potential endpoints.

Cognition occurs within a bounded system: our brains function in relatively predictable ways—neurons fire, signals are transduced, sensation becomes perception, and so forth—regardless of the specific information we are processing. Communication, too, occurs within a bounded system. Despite the seemingly unending rearrangements of words and expressions and gestures, the meaning of these rearrangements are predictably fixed within groups; it is almost impossible to say something utterly senseless. Brain based interventions can predictably work; the added bonus is, of course, that brains are highly efficient and incomparably economic. Cognitive strategies merely ask the brain to do what it does best; while system targeted strategies are doomed to lose all their momentum to entropy. Playing to the environment is an expensive model, not only in terms of money, time, and human resource expenditure, but in terms of *error*. The environment itself is not predictable; manipulating new pieces into it will hardly make it more so.

Taking the A-train: Achieving automaticity

Under similar conditions, with similar training, our brains work about the same; mechanisms of interpersonal communication remain the same, across situations, circumstances, and environments. The content of cognitions and communication may change, but the pathways are unaltered; just like a subway car carries different passengers to different locations throughout the day, while the train routes and schedules remain constant. And like express routes, some cognitive pathways allow faster, more efficient travel by removing intermediate steps.

Medical decision making begins as an explicit, controlled C-sytem process. Learning is incredibly slow (which explains the eight years of medical school) and deliberate, but the advantage is it results in complex thought networks that, with sufficient practice, will allow for mental shortcuts across pathways that, prior to learning, *didn't even exist*. With repeated travel and investigation of different pathways, our thoughts eventually become like New York commuters instead of tourists; they don't take the scenic route, they don't stop for hotdogs on 42nd, they just take the fastest route from point A to point B, even if it means switching trains five times to do it. Ask the same New Yorker for directions though, as a tourist, and they will likely tell you the most direct route, with the least amount of transfers, no matter how long it takes. The advantage of expertise is that shortcuts become second nature. What this means for clinical expectations and decision making is that, how clinicians say they arrived at a decision may not be an accurate reflection of how they *actually* came to that determination.

This is an important concept when suggesting that physicians should be the ones to shape expectations for families. Expertise results in automation of cognitions that are typically under conscious control; a knowing-without-really-knowing-how-you-know. Requiring physicians to condense expectations, which they have formulated through either years of medical education (controlled processes) *or* years of experience in practice (automatic processes) into the temporal reality of the family's presence in intensive care, is perhaps asking to much.

Discussion

"These aren't the droids you're looking for" –Star Wars

And now for the other questions...

General observations revealed elements of **who, what, when,** and **where** regarding expectations in clinical care. A further exploration of these issues in the context of the literature allows us to propose mechanisms explaining the **how** and **why** dimensions of expectation genesis. This section explores how

expectations are shaped intrinsically by the process of enculturation, and why extrinsic mechanisms of systematic change are unlikely to be effective or sustainable.

Enculturation as a vector for change

The medical profession capitalizes on a closely guarded secret: Enculturation is a pervasive, dominant, and meticulously efficient mechanism for ensuring compliance. It is also surreptitious and inescapable. This has two chief implications for intervention research: the first is that <u>training messages</u> which are inconsistent with the dominant culture are unlikely to be effective, and the second is that messages which are reinforced by enculturation require no formal training.

People change, but not much. Countless anecdotes lend credence to the assertion that fundamental changes in individual's behavior are unlikely. Consider how sexual harassment training modules in male-centric companies are regarded as humorous, or how cultural sensitivity training leaves the unenlightened making reminders to themselves about how to treat "those kind of people," or the ineffectiveness of anti-smoking or anti-drug campaigns, or the limited impact of nutritional information on eating behaviors. Knowing does not equal doing. Educating clinicians about ways to communicate with families does not change the ways that clinicians communicate with families; not in a meaningful or enduring way.

Speaking French in Chinatown. One of the problems with communication interventions is that they require people to encode communication information in a completely unnatural way. Everything we know about communication we learned by immersion; by being exposed to the communication of others, and by trial-and-error attempts at responding in kind. Communication is not acquired by explicit training; hence, extrinsic communication training interventions attempt to insert communication patterns onto a cognitive grid that isn't fitted for them. Much like learning a second language, this secondary acquisition of communication traits is less streamlined; when we try to fit new language words into our first language

grammatical structure, the result is often halting, not-quite-translatable speech that serves the purposes of neither the speaker nor the listener. Communication training does the same thing, by trying to fit new blocks of communication into existing structures. To assume that doing so would result in a new, fluent mode of communication is misguided.

Communication gone viral. I use the word "vector" to describe enculturation for a very specific reason. In bioengineering, vectors are a means of transporting new material into the body in such a way that the body will incorporate it, and not reject it. Viruses make for extremely versatile vectors, in that they use parts of the hosts body—components of cells—to do the dirty work of incorporating foreign agents. By doing so, the body does not recognize the virus as an invader; it has "clothed" itself like the locals, and learned to speak their dialect, and so the body does not bother to initiate an immune attack. Viruses are used in gene transfer. The virus must only be made to hold the desired gene, and then is injected into the body where it inserts itself, in disguise, into DNA. The result is that the cell "adopts" the new gene and puts it to work—doing the kinds of jobs that all genes do, making proteins that interact to make various products and carry out certain processes within the body. This technique has been used to cause cells to produce therapeutic agents naturally and continually inside the body, circumventing the need for ill patients to continue taking medications.¹¹

Cultural information is assimilated in much the same way. We do not perceive our values and beliefs as foreign, but as part of us. Even though they come from outside of us, from our environment, they are capable of influencing our behavior in monumental ways. Like the virus, they become a part of us at the deepest level, and our communication and behaviors are their products. To effect behavioral change that is consistently reproduced, that is not rejected, and that makes use of already-functioning systems, we must take a hint from geneticists; the change that is easiest for us to make is the one that doesn't really require us to change. Just as the virus fails to provoke an immune response (and in the end, actually boosts immunity), when it comes to changing communication, the best intervention may be non-

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¹¹ In reference to gene therapy for SCID.

intervention: assimilation of family-centered values via cultural transmission processes allows for long-term, self-replicating systematic change.

Social cognition

Smileys and ROFL: Don't IM without them. Social cognition refers to processes that occur in the brain when members of a species integrate information received from, or regarding, conspecifics (members of the same species). Social cognition includes such innate abilities of humans as the recognition of faces (infants prefer human faces, study) and the ability to encode nonverbal communication, including facial expressions, vocal prosody, and body position (kinesiology dot study).

Social cognition is an adaptive function in species that require interdependence; in essence, it makes information about other people automatic. In pre-lingual societies, the ability to interpret the facial expression of a stranger as friendly or hostile could have life-or-death consequences. In current society, automaticity of social cognition ensures that we can carry on complex activities in cooperation with other people, without requiring deliberate thought or communication; massive amounts of information are communicated by an exchanged glance, a head tilt, an averted gaze, or a slumped posture.

Most of has have experienced the kind of miscommunication that occurs due to a poverty of nonverbal behavior as a context for understanding exchanged verbal communication. In texting and instant messaging, we tend to use the same language structure we use when speaking. This is different than structures used when writing a letter or email, which typically contain more elaborative content.

Texts and IMs are produced with the expectation of an immediate exchange of information, but without the aid of facial expression, innocuous humor can seem offensive; without eye contact, intimate speech can seem superficial; without vocal inflection, irony can appear like intentional deception. The importance of nonverbal qualifiers for adequately interpreting verbal information is evidenced by the invention of emoticons ("smileys") to communication affect, and initialisms such as "LOL" (laughing out loud) or "SMH" (shaking my head) as a context for interpreting typed conversation, and our near-inability to communicate without them in texts, IMs, and other social media.

Making it work

Implementation of a dual process model of social cognition is a novel approach to understanding suboptimal communication between families of critical care patients, physicians, and other clinicians, based on underlying differences in neurocognitive processes. As such, further investigation is warranted among social cognition research to support the contextual application of this model, and to establish construct validity of the x- and c-system cognitive styles based on communication transcripts and self-reports of communication by clinicians and families. Similarly, further exploration of evidence-based links between dual-system processing and neuroeconomic constructs should be explored. Specific application of neuroimaging techniques in the assessment of critical-care decision-making by clinicians and non-clinicians could bolster support for psychosocial-neurocognitive theory based evaluation of healthcare communication and intervention design.

Meta-analysis of family-centered communication literature may further support a social-cognitive understanding of critical care communication and intervention design. Correlation analysis between communication obstacles addressed by literature-based, dual-process informed communication intervention and communication obstacles identified in site-specific data would be beneficial for identifying necessary and sufficient intervention components, to allow for highly efficient design implementation.

What this means for the system

Is satisfaction enough? Family satisfaction is a predominantly recognized measure of "success" in family-centered care and communication, as it has been demonstrated to predict shorter stays, faster recovery, and fewer lawsuits. While family satisfaction is not seen to be the final destination, but rather a marker of other broadly desirable endpoints which benefit patients, families, and clinicians alike, there is some question of whether the focus on family satisfaction is overly consumerist.

Alternatively, a claim that the true aim of family-centered care is not family satisfaction, but family *compliance*, would be difficult to dispute; the initial goal of the SEE project intervention was to avoid the *crisis*—defined as the communication event which precipitates the physicians need for an ethicist mediator (and colloquially described by one physician as "the crazy family protocol"). Unquestionably, physicians perceive the job of the ethicist in these situations is to "fix" the family—to them, this dispels the crisis. For the family, however, the true crisis—the condition of the patient—is unavoidable.

In surveys of family satisfaction, it is difficult to pinpoint exactly *which* elements of the care experience were *satisfying*, especially when the outcome is overwhelmingly negative. Consider the family of a young, previously healthy trauma victim who is being treated at a reputable hospital by a well-renowned surgeon. However, if the young patient dies unexpectedly due to complications of a necessary surgery, it seems difficult to conceive of this care as *satisfying*, even if the family believes they received the best care possible. Satisfaction as a construct is thus pliable to situational constraints and malleable over time.

A more stable and enduring attitude exhibited by families toward physicians is *trust*. Trust is related to satisfaction, but tends to represent family attitudes over time and across variable situations. While satisfaction is backward-looking, trust represents a "forward looking evaluation of an ongoing relationship" (Hall, Dugan et al. 2001). In predicting which patient will remain with their physician and follow treatment recommendations, trust is actually *better* than satisfaction (Thom, Ribisl et al. 1999).

A new king in town? Investigation into the implications of ethicist role-shifting form ethicist-as-mediator (counselor/confidant to patient) to ethicist-as-consultant (role-makers for physicians) is warranted; expert opinions should be considered from the perspectives of family-centeredness, healthcare policy and economics, and applied medical/healthcare ethics. However, it would be naïve to overlook the possibility of unintended consequences (Robert K. Merton; Adam Smith—consequentialism). The creation of a hierarchy within the field of ethics—with current "boots-on-the-ground" senior ethicists transitioning to positions of expertise in ethical consultancy—could easily result in less-experienced

junior ethicists, or non-career ethicists (clinicians operating in dual roles as ethicists), having more direct contact with families. This is not far afield from the increasing trend towards specialization in healthcare, which by some measures disservices patients and families by exposing them to less-experienced clinicians. Since decreased contact with highly experienced clinicians is directly related to decreased patient- and family-satisfaction, the impact of reduced family contact with experienced ethicist must be thoroughly investigated.

Burden of care. The specialized and demanding nature of medical practice, particularly at the level of specialist physicians, presents a significant burden both cognitively and practically. Interventions that target automatic (X-system) processes are unlikely to be effective, due to insufficient recruiting of these resources in clinical settings. Lack of dependence on the X-system for processing social information in clinical settings is largely attributable to hypertraining of C-system processes in medical education, reliance on C-system for recalling and integrating medical information, and supplanting of typical X processing by expertise-associated automaticity (medical, rather than social, features of patients become the subject of automatic processing, and potentially the depersonalization of patients, dismissing them as subjects of social cognition. Conversely, C-system dependent interventions are subject to cognitive load, and are deprioritized in comparison to medical information that is crucial in the context of practice. Training methods lack the efficiency and salience of culturally acquired information, thus trained communication information is supplanted by information gained by enculturation.

Specialization and fragmentation in healthcare is a successful means for improving quality and efficiency of care. In effect, family centered communication asks the physician to de-specialize; to generalize not in just medical care but in social dynamics as well. Such demands cause an undue strain on physicians, both cognitively and socially, and could significantly impair their abilities to provide high quality care. Moreover, there is little incentive for physicians to incorporate strategies which conflict with other aims: the physician's primary duty is to the patient, not the family, and time spent in conversation is not billable. Though attending physicians hold the greatest sway in influencing the

culture, and thus the family-centeredness of care and communication within a unit, requiring non-medical expertise from medical providers is likely compromises quality of care.

Synthesis

With the aim of cultural transmission of family centered values and communication strategies in mind, counterbalanced by a brain-smart, clinician-centered ethic of unburdening the already-cognitively-overburdened specialists, the question becomes, who will be the purveyor of this cultural information?

The burden of family-centered care logically sits with the ethicist; and the potential for enculturation is held by the attending: thus, the economic solution is the development of an attending ethicist role. Such a role would allow for provider (communicator) continuity, enabling a readier rapport with the family. The ethicist is better positioned than a physician to convey information in an unbiased manner, and to translate complex medical information to a level the family can comprehend. And, a more sophisticated understanding of the goals and means of achieving family-centered communication would result in higher quality, specialized communication with the family. In essence, the ethicist has a capacity for responsiveness to family dynamics, emotional states, questions, and concerns, that cannot be achieved by any other clinician.

Incorporation of ethics into the clinical setting also provides a substrate for cultural transmission of family-centered information to other clinicians. An ethicist in rounds could advocate for patient and family needs and realign communication toward family-centeredness in a context in which collaborative information exchange is formalized, and establishing concensus is primary. This strategy elevates family-centered communication to the level of medical care in terms of importance, without requiring disruption of routines or deliberate change of procedures on the part of clinicians. The information is at once owned by the ethicist and assimilated by the team in the standard concensus-making of rounds. If the family is present, this approach allows for a modeling of family-centered communication in real time, as the ethicist interprets medical information for the family, addresses their concerns, responds to their emotional states, and answers their questions. Family-centered values and communication skills are thus

acquired by physicians via exposure and immersion, the same means by which they incorporate experiential learning of medical information, with equal efficiency and salience. The ethicist, in effect, acts as role maker for the both the clinician and the family, shaping expectations for family-centered communication and care.

Future Directions:

"What we have here is a failure to communicate" -Cool Hand Luke¹²

Family-centered care literature has demonstrated numerous effective methods for improving family satisfaction in critical care and health care in general, yet these methods are not broadly implemented despite family-centeredness being almost universally accepted as a healthcare goal, invariably acknowledged in hospital mission statements, and having made its way into numerous healthcare policies. While new intervention studies abound, research in long-term adherence and sustainability are lacking.

Lemons and horsemeat

Besides sustainability, also absent in the body of communication intervention literature is research regarding the mechanisms of intervention efficacy. A multitude of methods have demonstrated the same effect—increased family satisfaction—yet little is known about which components of these interventions are both necessary and sufficient for achieving intervention goals. This can be likened to pre-twentieth century treatments for scurvy: Sailors subsisted primarily on non-perishable diets of cured meat and dried grain until it was recognized that such limited nutritional regimens were associated with disabling, and often deadly, bouts of scurvy. Admirals' informal between-group comparisons of sailors

¹² The actual quote was, "What we've got here is a failure to communicate"—but the above misquote has been widely popularized and is far more recognizable.

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on different voyages inevitably revealed reduced incidence of scurvy among sailors who had access to diets including fresh food items as diverse as lemons, watercress, and horsemeat; hence, fresh citrus fruit, vegetation, and meat consumption on sailing ships was advised by Surgeon Generals, and scurvy morbidity among sailors was dramatically reduced. However, due to the excessively long and oftentimes unpredictable nature of some sailing routes (and the complete deficiency of transoceanic lemonade stands), many sailors still died of the disease when fresh food supplies dwindled.

In 1747, Scottish physician James Lind published *A treatise on scurvy*, documenting what historians refer to as the first ever clinical trial, which implicated vitamin C—a component of fresh fruit—as the *necessary* and *sufficient* nutritional component for scurvy prevention. Lind was right, but his proposed intervention—extracted lime juice—failed, because Lind was unable to predict the oxidation of vitamin C that occurred after the juice was exposed to air, which rendered the vitamin unviable for treatment. It was not until over a century later in 1867, when Lauchlan Rose developed the first alcohol-free process for preserving lime juice, that widespread prevention of scurvy was possible: preserved vitamin C was recognized as the necessary-and-sufficient treatment component, and Rose's Lime Juice Cordial became the uncontested prescription of choice of admirals everywhere—an intervention that had the added bonuses of being pragmatic, efficient, sustainable, and profitable. The treatment was immediately adopted as a matter of policy in the Britain's *Merchant Shipping Act*, resulting in an industry-wide eradication of the scurvy epidemic.

The dangling question is, are communication interventions for physicians the lemons-and-horsemeat of long-departed sailors? Are we offering unwieldy talk treatments that pack comparatively little punch in relation to their bulk, and are difficult to sustain over the long haul? Are hospitals overspending for physicians to overconsume the fruits of family-centeredness, only to see our stockpile spoil or run out? Might it not be worthwhile to identify the vitamins of communication, and figure out how to preserve them?

Let's get Cordial

The elegance of a social cognitive / neuroeconomic approach to understanding communication is that, despite our intricacies and uniqueness, human cognition and behavior is amazingly predictable.

Rather than invoking endless iterations of what *might* work (lemons and horsemeat), just to add them to the archives of what's been demonstrated to be *minimally* effective for short periods of time and under artificial constraints (Lind's vitamin C extraction); we can economize by simply doing what works, and if needed, doing more of it.

What works in the BICU, and in Vanderbilt's other critical care units, is the ethics consult. Ethicists provide face-to-face, objective, empathetic communication with family members that resolves conflicts with clinicians, helps families understand the patient's conditions, and draws decision-making out of the foreign territory of medicalization of person-as-patient and into the familiar realm of patient-as-person-in-family-in-context. Expanding the role of ethicist involvement with families in critical care—from emergency lemons for sick sailors, to a universally prescriptive and preventative cordial for all seafarers—requires a conceptual assimilation of family care *as* healthcare. Family-centered communication, and family integration into the patient care plan, must transition from contingency plan to de facto protocol in critical care delivery.

Boots on the ground

Families need guidance in forming expectations and making decisions in critical care, but that doesn't mean the physician should be the one to provide it. The advances we see in health care over the past century have only been possible because of specialization. To ask our doctors to now take a step backward and become generalists in not just human biology, but in behavior, cognition, communication, and socialization as well does a tremendous disservice to both doctor and patient. The duty of our health care providers is to the patient; in this regard the clinician and family member are equals. But when family members are rerouted from being active participants in providing care to the patient, to being

unsatisfied consumers who need their doctors to do *more* than just save the patient's life—the practice of medicine is turned on its head.

Just as physicians specialize in order to push back the boundaries of illness and injury, the role of ethicists is to specialize in the just treatment of persons within their care; it is not enough—nor is it even required—to insist that others meet this same challenge. Ethicists are best prepared to deal with the complexities of family dynamics in the ecosystem of the intensive care unit. In a clinical setting, the ethicist is the ideal rolemaker for patients, families, and clinicians. The presence ethics role within the hospital unit lends credence to hospital mission statements of patient-and-family-centered care; the ethicist is the consistent advocate, mediator, educator, and counsel of patients and family members. The role of ethicist-as-onlooker must give way to boots-on-the-ground ethicists who will lead the frontline in family-centered care.

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