# INTEGRATIVE EXPLORATION OF THE PRIMARY CARE INTERACTION:

# TENSIONS AND IDEALS IN PATIENT-CENTERED CARE

by

Brian M. Rahmer

A dissertation submitted to the Faculty of the University of Delaware in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Urban Affairs and Public Policy

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I am thankful for and encouraged by both the family medicine resident physicians and their patients who consented to participate in rather intimate research. Many expressed hope that their participation might elicit change for the better. Their words and actions were not just recorded, coded, and analyzed; they were *listened* to.

The long-term goal of this research is to support and nudge the thoughtful transformation of health care, more broadly, into a collective effort built around patient and community needs – physical, psychological, social and structural. This system of care must not only meet those needs effectively, but do so in a way in which patients have ultimate agency and authority. As such, I am thankful for all of my co-workers and partners who work tirelessly towards this goal, in solidarity.

I reserve my last and most significant acknowledgement of love and appreciation for my wife Juliana, daughter Gabrielle, son Joseph and our brand new addition, Emily Rose. You give me more than I could ever dream of giving back.

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**ABSTRACT**

Communication matters in medical encounters. Health care providers, patients, researchers and policy makers are well aware that good communication is the basis of an effective relationship between care providers and patients. In an era of dynamic health care reform, institutional strategies emphasize re-organizing health care system components and incentive structures around patient-centered care as means to improve health and lower cost. However, examination of the complexity of the association between elements of patient-centered communication and macro (policy), meso (institution), and micro (interaction) influences on such care is still relatively novel.

This exploratory research explains how and why dimensions related to patient-provider communication are critical to understanding and optimizing political, institutional, and individual goals of health care reform efforts. I explored patient-provider interactions within primary care practice using an integrative social analysis framework with a primary objective of building on the theoretical understanding of how individual, organizational and political goals may produce tensions in patient-centered care. These tensions were highlighted as potential points of innovation. Results generated by the proof-of-concept methodology used in this study reaffirm the need to account for both micro and macro level influences linking patient-provider communication to broad health outcomes. Patient-centered care was critically

interpreted using a multi-level approach including interaction analysis of real conversations between primary care physicians and diabetic patients as well as a novel video-elicitation method to account for context within a cultural-historical framework. Theoretical contributions include the integration of patient-centered communication patterns within primary care interactions with the elicitation of barriers and facilitators of patient-centered care. This analysis was used to recognize tensions, contradictions and ideals in patient-centered care that can be used in critical analysis of healthy policy, health system strategic planning, and practice level reforms.

What does it mean to be "patient-centered" and what does this then mean about ways of improving health care systems, communication and translation of knowledge? Putting a primacy on understanding the interaction between the patient and the provider may indeed be the only way in which the quality of health care delivery is improved; especially in a reform-oriented care delivery system which emphasizes and incentivizes patient-centeredness.

**Chapter 1**

**INTRODUCTION**

The Patient Protection and Affordable Care Act (Public Law 111-148, ACA,
"Obamacare") ushered in an historic expansion in health insurance coverage designed
to provide around 32 million low-income Americans greater access and more choice
in where and how they receive their health care (Congressional Budget Office, 2012).
Under the Affordable Care Act, the United States has turned its attention to improving
the quality of health care while simultaneously decreasing cost through an emphasis
on team-based patient-centered care delivery and accountable, outcomes based
reimbursement driven by value instead of volume. A primary method of delivering on
this policy goal is by incentivizing and prioritizing a Patient Centered Medical Home[1]
(PCMH) model of care delivery organized within an Accountable Care Organization[2]
(ACO) framework (Devers, Burton, & Berenson, 2011; Longworth, 2011). These
models have been promoted to expand access, improve coordination across the

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[1] The patient centered medical home is best described as a model or philosophy of
primary care that is patient-centered, comprehensive, team-based, coordinated,
accessible, and focused on quality and safety. It has become a widely accepted model
for how primary care should be organized and delivered throughout the health care
system, and is a philosophy of health care delivery that encourages providers and care
teams to meet patients where they are, from simple to complex conditions. (Patient-
Centered Primary Care Collaborative, 2009)

[2] ACOs consist of providers who are jointly held accountable for achieving measured
quality improvements and reductions in costs. (McClellan, McKethan, Lewis, Roski,
& Fisher, 2010)

continuum of care, promote quality, and reduce growth of costs. Primary care is a key element of the PCMH, as the first contact for care and for coordination with specialty and hospital services. The PCMH model endorses patient-centeredness to meet patients' full spectrum of needs, practice resources (e.g., electronic medical records, patient registries) to support evidenced-based care, and payment reforms to reimburse for care coordination and high performance. Accountable care organizations are provider groups responsible for the continuum of quality of care as well as the overall costs for a defined population (Rittenhouse, Shortell, & Fisher, 2009). Successful implementation of these nested models requires substantial cultural and organizational transformation within traditional and legacy health care institutions in order to achieve delivery system reform goals of the Affordable Care Act.

Barbara Starfield, a leading authority on primary care, emphasizes four pillars of primary care practice: first-contact care; continuity of care over time; comprehensiveness, or concern for the entire patient rather than one organ system; and coordination with other parts of the health system (Starfield, 1998). Primary care practice generally involves the widest scope of health care, including patients of all ages, patients of all socioeconomic levels, and geographic origins, patients seeking to maintain optimal health, and patients with multiple chronic diseases (Starfield, Shi, & Macinko, 2005a; Wolff, Clayman, Rabins, Cook, & Roter, 2012).

The patient-centered medical home has emerged as the primary care practice model to address Starfield's concept in a structural manner aimed at reducing costs by coordinating care efforts, utilizing health information technology and, ultimately, obtaining higher quality and better health outcomes for patients (Crabtree et al., 2011; Takach, 2012). The concept of the PCMH is woven into the Patient Protection and

Affordable Care Act (ACA) and broadly defined in Section 3502 to further population health initiatives for communities, as well as preventive health and ongoing care for chronic illnesses, among other care aspirations. As stated in Section 3502 of the ACA, healthcare providers involved in medical homes should "develop and implement interdisciplinary, interprofessional care plans that integrate clinical and community preventive and health promotion services for patients" (Congress, 2010).

Additionally, patient engagement is central to Section 3021 of the ACA, which established the Center for Medicare and Medicaid Innovation (CMMI) (Congress, 2010). Under the law, the innovation center is tasked with examining how support tools can be used to improve patients' understanding of their medical treatment options, and how these tools are implemented across patient population. The Patient-Centered Outcomes Research Trust Fund (PCORTF) was authorized by Congress from fees imposed under the ACA's subchapter B of chapter thirty-four (34) (Congress, 2010) as a means to fund the Patient-Centered Outcomes Research Institute (PCORI), at least through September 30, 2019. PCORI is charged with funding outcomes research with a focus on research that addresses participatory, patient-centered approaches in the delivery of health care, payment reform and incentive structures, and innovation practice models (Sox, 2012).

This political and institutional interest in the patient centered medical home and patient-centered approaches to the delivery of health care has placed patient-centeredness, once again, at the forefront of an evolving healthcare ecosystem. The terminology is now widely used but may be most commonly understood for what it is not; technology centered, doctor centered, hospital centered, disease centered. As such, definitions of patient centered care seek to make an innate value in patient care

more explicit. Consequently, such definitions are often steeped in oversimplification, which may help in teaching and research to a degree, but fail to capture the intrinsic nature of engagement through a patient-centered healing relationship.

## Background

In the United States, federal health care legislation, patient advocate and health policy organizations, and grassroots groups are all emphasizing the need for health care to be more explicitly centered on the needs of the patient while involving the patient in care decisions (Berwick, 2009; Singer et al., 2011; M. Stewart et al., 2000; Taylor, 2009). Quality and safety agencies (Davis, Schoenbaum, & Audet, 2005; Doyle, Lennox, & Bell, 2013) and structural healthcare reform initiatives (Frankel, Eddins-Folensbee, & Inui, 2011; Institute of Medicine (US). Committee on Quality of Health Care in America, 2001) all prioritize the philosophy and practice of patient-centered care as being essential to achieving outcomes related to health care's Triple Aim: improving the patient experience of care (including quality and satisfaction); improving the health of populations; and reducing the per capita cost of health care (Berwick, Nolan, & Whittington, 2008a).

While enjoying a concentrated focus and awareness in health policy, health services research and social science research over the last two decades, an emphasis on patient-centeredness continues to suffer the absence of consensus regarding its definition and conceptualization. Whereas van Dulmen describes patient-centeredness as a "fuzzy concept," Epstein and colleagues outline patient-centeredness as a "multifaceted construct, like intelligence". Furthermore, Hobbs distinguishes patient-

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centeredness as a "poorly conceptualized phenomenon" (R. M. Epstein et al., 2005; Hobbs, 2009; van Dulmen, 2003).

Although there is less agreement on how to make patient-centered care a reality in everyday clinical practice there is little argument against the tenets of its overarching philosophy (Bertakis, Franks, & Epstein, 2009; de Haes, 2006; R. M. Epstein et al., 2005; Sox, 2012). This includes how patient-centered care is conceptualized in policy-level recommendations and interpreted at an organizational-level, and ultimately translated into action at the patient-provider level. The seminal texts from health policy, social science and medicine (with particular emphasis in primary care) are relatively consistent in the philosophy of patient-centered care which includes variations of the following eight themes: (1) respect for the patient's values; preferences, and expressed needs; (2) coordinated and integrated care; (3) clear, high-quality information and education for the patient and family; (4) physical comfort, including pain management; (5) emotional support and alleviation of fear and anxiety; (6) involvement of family members and friends, as appropriate; (7) continuity, including through care-site transitions; and (8) access to care (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Mead & Bower, 2000; Mead, Bower, & Hann, 2002; Starfield, 2011; Waitzkin, 1991a).

Health policy analysts, researchers and health care providers, such as primary care practitioners, tend to focus as much on the wider system and contextual issues of the patient-provider relationship, while the more technically-driven discourse is constructed around a very clearly delineated therapeutic relationship between the individual medical professional and the patient. Within this arrangement of the research, it is clear that patient-provider communication is a central construct in the

overarching paradigm of patient-centered care (R. M. Epstein et al., 2005; Joint Commission, 2010; Makoul & Clayman, 2006a; Suchman, 2006; Zoffmann, Harder, & Kirkevold, 2008). Patient-centered communication includes the patient perspective, and the psychosocial context along with shared understanding, power, and responsibility in health and well-being (Bensing, Rimondini, & Visser, 2013; Deledda, Moretti, Rimondini, & Zimmermann, 2013; Todd & Fisher, 1993). Effective patient-centered communication has been consistently linked to better health outcomes and lower cost of care (Hibbard, Greene, & Overton, 2013; Oates, Weston, & Jordan, 2000; Roter & Hall, 2006; M. A. Stewart, 1995).

On the one hand, patient-centered care is considered a skill we can approach by observing communication and behaviors that occur during the interaction between the patient and provider and thus assign meaning through empirically informed value judgments. On the other hand, it is viewed as a "way of being" in relation to other influential processes, norms, and models of care delivery nested within structural institutional and societal domains. This highlights both the intangible and observable experiences of the actors in the dyad and inquiry into this subject requires a contextual assessment of the facilitators and barriers to eliciting patient-centered care. Both points of view require theoretical analysis and research that weaves multiple approaches but few studies are available that approach these perspectives collectively.

## Problem

The fundamental interaction in patient-centered health care is the one between patient and provider. If the patient-provider relationship is to be health care's touchstone, however, all parties must understand the essence of that relationship and

the relationship itself must be sound. Achieving these goals requires clearly articulating the expectations of both patients and physicians and then reconciling expectations that may conflict. While policy makers, academics, payers, and providers have emphasized the importance — and necessity — of engaging patients differently and more effectively within an environment of patient-centeredness, there have been few data and a limited scope of scalable examples to inform critical discourse. Furthermore, researchers rarely address, if they even acknowledge, the need to situate patient-provider communication within the broader context of physiological, personal, and socio-ecological determinants of health.

Although inquiry into medical encounters involves "micro-level" interactions between individuals, these relational processes occur in a social context shaped by "meso-level" organizational effects and "macro-level" policy and socio-ecological influence . Therefore, improving the delivery of patient-centered care requires systematic practice change (e.g. the patient-centered medical home), increased awareness by providers, the support of institutional stakeholders and policy makers, and perhaps of utmost importance, the active engagement of patients (M. J. Barry & Edgman-Levitan, 2012; Ferrante, Balasubramanian, Hudson, & Crabtree, 2010; Levinson, Lesser, & Epstein, 2010a). Such improvements in the delivery of patient-centered care and the institutions which support it may be even more crucial for patients with chronic, complex health care needs such as diabetes and its related comorbidities (Bundesmann & Kaplowitz, 2011; Kruse et al., 2013; Polonsky, Zee, Yee, Crosson, & Jackson, 2005). Success in deriving value from health care interactions among patients with chronic disease is measured by achieving health outcomes that matter most to patients (Nam, Chesla, Stotts, Kroon, & Janson, 2011).

Research surrounding patient-provider interactions has differed in its epistemological underpinning (Salmon, Mendick, & Young, 2011). Two distinctions have been made, based on the source of knowledge and the format of data collected. First, researchers often choose between self-reports from those involved in the interaction (emic) or an observer's (etic) classification of the event (Saba et al., 2006). For example, a post-consultation survey completed by a patient, versus, analysis of a video-recorded interaction by a researcher. Secondly, data has been collected in a quantitative or qualitative format (Neumann et al., 2011). For example, analysis of a video-recorded interaction by counting the number of utterances in a coding category, versus, identification of the main themes within the interaction interpretively reported within a structural framework (Kreps, 2011).

Historically these approaches have been applied independently throughout the research (Bryman, 2006; Zoppi & Epstein, 2002) which may serve to limit the kinds of conclusions that can be drawn from inquiry into patient-provider interaction (R. M. Epstein & Borrell-Carrio, 2005; Teal & Street, 2009). Researchers approaching the study of interactions between patient and providers from only one perspective would, therefore, fail to acknowledge empirical data, context, and insight which may have important theoretical and practical implications.

**Purpose**

As noted in the previous sections of the introduction, the primary care system in the Unites States is currently undergoing changes which emphasize and incentivize a model of patient-centered care delivery within a patient-centered medical home. This concern is driven primarily by health care reform policy goals orienting towards the

achievement of the "Triple Aim", an informed call to action for improving the U.S. health care system by simultaneously pursuing three goals: improving the experience of care, improving the health of populations, and reducing per capita costs of health care (Berwick et al., 2008a).

Of all aspects of the health care enterprise, the interaction between the patient and provider will be the subject of this research. Specifically, the primary focus of inquiry is the interaction between individuals with a chronic condition, diabetes, and resident primary care practitioners within family medicine practices designated as Patient-Centered Medical Homes (PCMH). While this choice has been influenced by practical considerations given the nature of this researcher's work, it certainly has theoretical advantages, described as follows.

Primary care is the foundation of the evolving health care system which is placing primacy on patient-centeredness. Further, a visit to the primary doctor is the most common experience of the medical system for the average person and even more so for the diabetic patient (Bodenheimer, Chen, & Bennett, 2009; Dall et al., 2010; Goroll & Mulley, 2012). Diabetes as a chronic illness is often accompanied by various comorbidities and complications controlled through both clinical management and sustained behavior change by patients driven primarily through effective communication (Bojadzievski & Gabbay, 2011; Kruse et al., 2013). Diabetes continues to be one of the most expensive chronic illnesses affecting over 23 million Americans at a cost of $245 billion in 2012 (American Diabetes Association, 2013). Despite the direct and indirect expenditures for diabetes care, few diabetics are able to manage the disease in a manner sufficient to meet evidence based recommendations (Herman, 2013). Evidence strongly suggests that patient-centered care driven by

quality communication in primary care is the optimal environment for management of chronic diseases such as diabetes (Castro, Wilson, Wang, & Schillinger, 2007; Mohr, Benzer, & Young, 2013; Schillinger et al., 2003; Sudore et al., 2009).

Where patient-centered communication is needed the most in guiding patient-centered care, is arguably where most medicine occurs. Primary care providers, most notably family medicine practitioners providing chronic disease care within the community, are the first stop for patients and offer the backstop for patients with multiple chronic conditions. As primary care practices in both urban and suburban settings evolve their multicultural identities to meet the needs of the population balance shifts, excellent communication within a patient-centered model of care at the grassroots level of communities is a necessity.

Patient-centeredness has gained importance over the last two decades. Currently, there is an absence of theoretical clarity regarding patient-centered care and how political and organizational goals influence its delivery at the micro-level. This often results in inconsistent concepts, measurement and implementation of patient-centeredness, which leads to difficulties in comparing research results, translating results to practice, and defining attainable and meaningful policy goals around patient-centered care. In an effort to mitigate these difficulties this research aims to address the following research questions within a social theory construct.

## Research Questions

The following research questions are constructed within the frame of exploratory research into a topic, patient-centered care, which is approachable from many levels of examination. Given my interest in critical inquiry, I attempted to

address the following two research questions through critical discourse and integrative social analysis.

1. How is patient-centered care reflected in the observable interaction between family medicine primary care residents and diabetic patients within a primary care patient-centered medical home?

2. What are the barriers and facilitators, from a provider perspective, to implementing patient-centered care within this patient-centered medical home setting?

## Research Approach

The accumulated research around the movement toward the delivery patient-centered care suggests a logic model where policy influences a change in practice which then must lead to a change in the relationship between the patient and the provider in order to directly affect the outcomes elicited by policy, i.e. the Triple Aim of improving the patient experience, improving the health of populations, and reducing per capita cost of care (Berwick, Nolan, & Whittington, 2008b). This logical approach presents a challenge for social theory in clarifying how macro-level social structures and micro-level processes affect one another.

I assume a socio-ecological approach for understanding the interdependent nature of health, health care, and the health-care system, built around the notion of health as a personal experience. I frame health, individual health as well as the health of populations, as a demonstration of the interdependence of structure, purpose and process, reinforced by the properties of individuals, organizations, and the social structures in which they operate. This occurs despite constant change arising from the ordered relationships between the system's agents and actors. Further, I propose that

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the major interrelationships within the ideal health system can be elucidated around the core-driver of the personal interactions that occur between two main actors, the patient and the provider. From the individual level upwards, all other layers or levels within health care would be arranged within the familiar macro, meso, micro levels. Interactions would be operationalized by working towards the common goal of meeting patients' needs. Though interactions might appear to be specific to a particular level, they would always also affect all other levels of the system, and vice-versa.

The layers in the health system should be seen as dynamic and co-evolving, rather than hierarchical. Each layer represents a particular contextual domain that function as a whole, however, any action at any point in the system has the potential to resonate within the whole and affect all its agents. Equally, major activity at one level may have very little impact on the whole. For example, policies and funding changes around attention to chronic disease like diabetes may potentially shift power, resources and behaviors that impacts the way care providers communicate with diabetic patients. In this ecological model, the whole system's functionality is responsive to the core driver of patient-centered communication.

In an effort to address this concern for the sake of inquiry, a visual representation of the ecological approach to functional patient-centered care described above is presented in Figure 1. Ecological Model of Functional Patient-Centered Care. Examples of influences within each domain are provided for illustration and are defined explicitly in the definitions of terminology section at the end of this chapter, and in more depth throughout Chapter 2, Review of the Literature.
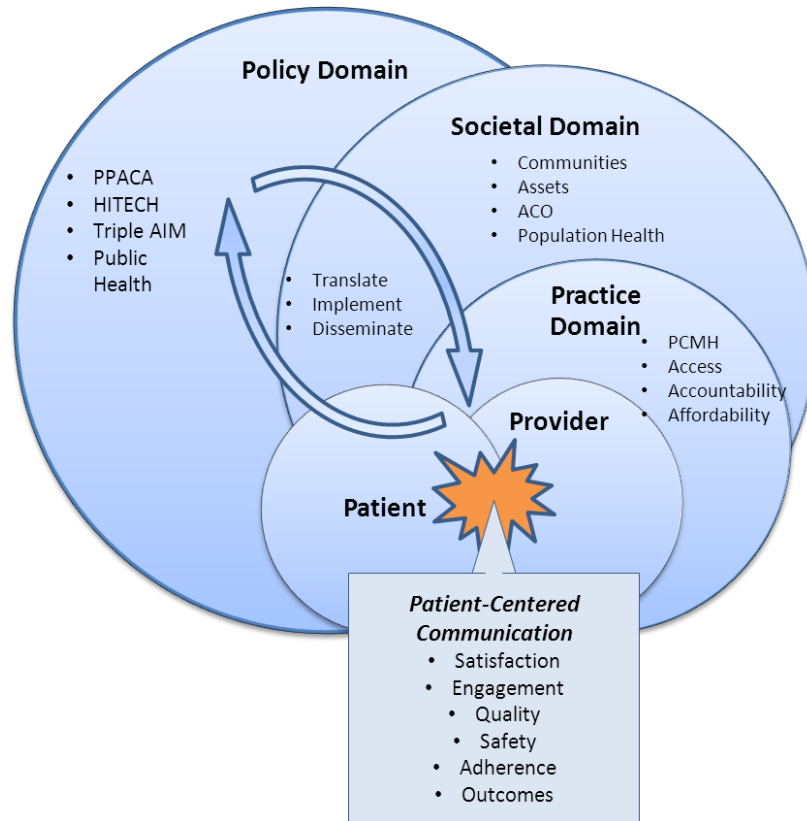
Figure 1.    Ecological Model of Functional Patient-Centered Care


This model reflects the integrative capacity of the ideal health-care system in which the socio-political domains would set broad policy directions reflecting the core values of dynamic patient-centered care and would coordinate these with other social and economic policy areas. The community health level would translate the broad policy direction into unique local service arrangements according to community health needs and local health care providers and other professionals, through their individual interactions with citizens-as-patients, would deliver patient-centered services that reflect both patient need as well as overall policy goals. In this model, each actor's activity would be shaped by his or her socio-environmental context in an aim to

achieve the best and most appropriate agreed upon outcomes for each patient. These nonlinear interactions would result in different but mutually consistent outcomes reflecting local circumstances, resources, assets and constraints.

The outcomes generated by such a health system as proposed in Figure 1 would contain a well-functioning, focused and responsive health workforce consisting of self-reflective professionals who are attentive to all community health determinants and health care needs. Attention to important social determinants for equity in health would include among others, safe and secure housing and proper sanitation, sufficient access to healthy foods, education and employment opportunities, and infrastructure for supportive social assets (E. A. Baker, Metzler, & Galea, 2005; Marmot, Friel, Bell, Houweling, & Taylor, 2008; Wilson, 2009). Inadequate attention to these factors results in marginalization and inequality, which in turn drives poor health outcomes (Wilkinson & Pickett, 2006; Willson, 2009). Primacy is placed on individual health needs within communities, even when political, organizational, and health service priorities change. In this model, accountability for this type of responsive health care system would be distributed among all agents and all levels.

The catalyst that drives the dynamic interaction within and between domains in Figure 1 is the collective element of patient-centered communication at the core of the interaction between patient and provider. These communication elements are represented below in Table 1. Functional Quality Communication in Health Care Delivery as a matrix of themes, goals and endpoints related to observable functional elements of quality communication in patient-centered care. This matrix was constructed using examples of theoretical constructs, elements of communication, and critical outcomes related to effective communication in the primary care setting. The

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supporting literature which informs the choices made in this functional framework can be found in (Bird & Cohen-Cole, 1990; de Haes & Bensing, 2009; R. Epstein & Street Jr, 2009; Heritage & Maynard, 2011; Keller & Gregory Carroll, 1994; Lazare, Putnam, & Lipkin Jr, 1995; Makoul & Clayman, 2006a; Teal & Street, 2009).

Table 1.      Functional Quality Communication in Health Care Delivery

| | Functional Model for Quality Communication in Health Care Delivery | Goals | Immediate Endpoints | Intermediate and surrogate endpoints | Long-term endpoints |
|---|---|---|---|---|---|
| 1 | Fostering relationships | Effective alliance | + eye contact +patient participation - stress | + trust +rapport +satisfaction with interaction | + patient engagement + health outcomes - physician stress/burnout |
| 2 | Gathering information | Adequate diagnosis and/or interpretation of symptoms | + explorative behavior + expression of patient concerns + identification of goals | + adequate diagnosis and treatment plan + quality measures - unnecessary tests - medical errors | - patient uncertainty + patient autonomy |
| 3 | Providing Information | Effective provision of information | + explore prior knowledge + check understanding - Use of jargon | + recall + understanding + activation | + satisfaction + health outcomes |
| 4 | Decision Making | Decision based on information and preferences | +check goals + identify values + shared decision making - paternal | - decisional conflict + satisfaction with decision +decision addresses goal(s) | + health outcomes + sustainable activation + advocacy potential |
| 5 | Enabling treatment and health promoting behaviors | Adequate and feasible treatment and disease related behaviors | + address motivation and efficacy + address socio-ecological barriers | + activation + adherence + lifestyle + barriers limited | + health outcomes +quality of life - barriers |
| 6 | Responding to emotional and social needs | Support, enhancement of communication and referral/coordination when needed | + clinician explorative skills + patient expression | + therapeutic alliance + patient sense of support + psychosocial | - distress + emotional adjustment + quality of life |

The framework that grounds the integrative methodology introduced in this research can be found in Figure 2. Integrative Model of Social Analysis, a visual representation of George Ritzer's description of integrative social analysis (Ritzer, 1990).

Macroscopic

| 1. Macro-Objective | 2. Macro-Subjective |
|---|---|
| Examples – Society, Policy, Laws, Environment, Technology, Language | Examples – Culture, Norms, Values |

Objective ← → Subjective

| 3. Micro-Objective | 4. Macro-Subjective |
|---|---|
| Examples – Patterns of Behavior, Actions, Interactions | Examples – Perceptions, Beliefs, Tacit Knowledge, Social Construction |

Microscopic
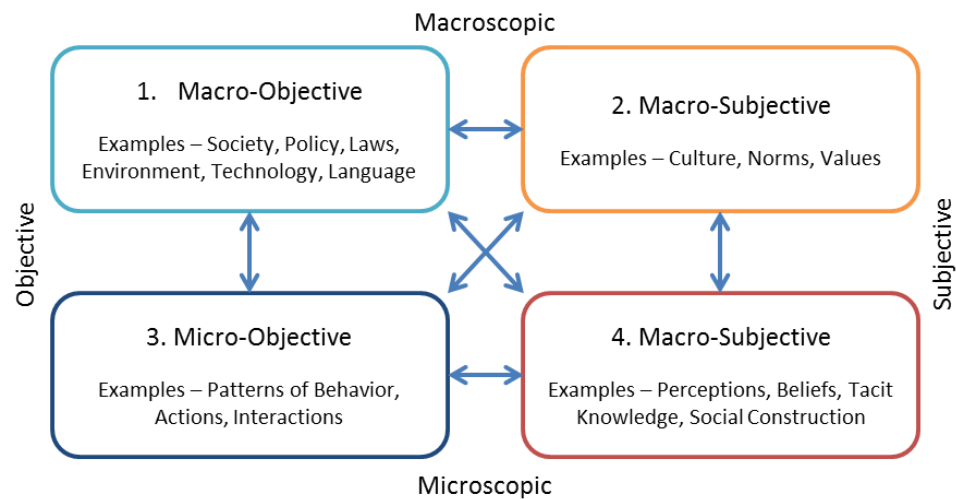
Figure 2.      Integrative Model of Social Analysis

This model of social analysis attempts to construct an *integrated sociological paradigm* built upon two distinctions: between micro and macro levels, and between the objective and subjective. This approach to my analysis is helpful not only in framing my methodological choices in answering the stated research questions but also in organizing those choices in a manner that informs the influence that occurs within and across the domains of Figure 1. Ecological Model of Functional Patient-Centered Care. For example, in the introduction and background sections of this

proposal I have laid out the political and institutional influences on patient-centered care at the macro-objective level. In answering research question number one, I engage a micro-objective exploration of patient-provider interactions through a structured coding and interpretive methodology based on a tested framework of patient-centered communication.

In addressing research question number two, I elicit providers' (one set of actors of the dyad) interpretations of the barriers and facilitators to implementing patient-centered care through a qualitative video-elicitation method. This method is chosen for its ability to provide insight into the micro and macro-subjective levels represented in Ritzer's framework. It is important to note that these social constructs are not conceptualized as dichotomies, but rather as continuums within which dichotomies and conflicts might exist.

In Chapter 5 of this dissertation, analysis and interpretation of findings, I interpret these data in a critical manner aimed at integration. Synthesis of the micro and macro influences explored in this research was achieved using a model of analysis informed by cultural-historical activity theory (Bleakley, 2014; Stetsenko, 2008). This construct is explained in more detail in the conceptual framework section of Chapter 2, Review of the Literature.

Regarding methodology and methods specifically, I used the activity theory framework to guide interpretation of the tensions, conflicts, and disincentives that emerged within and between the micro and macro levels of patient-centered care activity (Bleakley, 2014; Engeström, 1993). I engaged this method of reasoning with an aim to understand how seemingly contradictory forces that influence and impact the delivery of patient-centered care can be recognized, acknowledged and utilized as

potential areas of focus in eliciting innovative change at the individual, organizational and systems level. This approach provided me with an evolving tool-kit of means to make sense of activities and practices within a framework for which social context, history and change are central.

## Researcher Perspectives

*"All meanings, we know, depend on the key of interpretation."*

-- George Eliot, *Daniel Deronda* (Eliot, 1876)

I had many intertwined roles while carrying out the research described in this dissertation. I primarily acted as a full-time researcher, employed by the health system within which this research was conducted.  I framed elements of this study within the context of my doctoral dissertation. Furthermore, I acted as an interviewer and observer, both interviewing residents and observing activities carried out by residents who either formally or informally knew me, my role within the health system, and the context of my work.

In applying the activity-theoretical orientation, I viewed all research conducted as interventions affecting those being researched. For example, a patient's knowledge that her visit with the resident physician is being video recorded as a means to assess patient-centered communication skills may itself impact the type of discourse that emerges. As a researcher, I took a more active role while carrying out this project. It may be that the methods utilized in this study influenced and perhaps interfered with response and activity authenticity. It is crucial for the reader to note that my attempt in this research is not to address any specific issues concerning the quality of health care

work; but to better understand how changing and evolving health care environments influence and are influenced by policies, systems, and activities related to the conceptualization and delivery of patient-centered care.

The unit of analysis for this research is the interaction between the primary care provider and the patient. I apply a critical theory to analyze health care change efforts and make their consequences visible to widen our understanding of implications for patient-centered care, particularly within primary care practice.

## Rationale and Significance

*The philosophers have only interpreted the world in various ways;*

*the point is to change it.*

-- Marx's eleventh thesis on Feuerbach, (Marx, 1845)

Any professional practice is always thoroughly embedded in the social and cultural matrix of its society, and the health care profession in America is no exception. This research is designed as a novel approach to answer questions around the implementation of patient –centered care. Outcomes may indeed serve to codify the argument that the physician-patient dyad is grounded in an interpersonal relationship and that the biomedical model, relational communication theory, and the patient- centered approach to primary care delivery are not mutually exclusive. As outlined in the discussion, previous studies have linked interviews of patients and practitioners with observations of their consultation. Some approaches have included interviews with only one party or have just used consultation data to prompt interviews. Yet other approaches have been concerned primarily with conversational

processes within the consultation (typically about specific topics such as medication or decision-making) and not directly with effects mediated through their function or meaning for participants. Researchers have examined patient-provider interactions and interview data in relation to specific theoretical constructs, including engagement, activation and empowerment. However, there is growing evidence showing that one-dimensional understandings of the relationship based solely on observing consultations, or solely on interviewing either the patient or the provider, are incomplete and potentially misleading in guiding both theory and practice. The importance of the integrative methodology in this research is to go beyond simply describing agreement or disagreement between perspectives. Instead, my intent is to integrate these perspectives in analysis to show that it is possible to identify new ways of conceptualizing the clinical relationship; perhaps to build on methods towards improvement in theory. This is driven by the notion that even explicit research-driven evidence-based medicine rests on a backbone of implicit or tacit knowledge. This presents a general challenge in theoretical orientation to patient-centered medical practice. Emphasizing the role of tacit knowledge enhances the idea that those who make or participate in shared medical judgment are not abstracting from rational points of view but deriving consensus as embodied agents who share relational objectives. It is this shared practical orientation that underpins conceptual judgment and reliability between different clinicians, different patients, and different partnerships of the two.

This effort is framed by the integrative approach to analysis that I have described in both the literature review and methodology chapters of this dissertation and is grounded in the political and organizational push towards mechanisms at the

individual, practice, and system levels to encourage patient-centered approaches in care delivery. A critical understanding that guides my research is that patient-centered care contrasts with an over-concentration on symptoms considered in isolation, the embodiment of a traditional legacy approach to biomedical sciences. The methods used in this research acknowledge that the technical delivery of patient-centered care also has a philosophical correspondent apropos to primary health care delivery, especially as embodied in the Family Medicine specialty. This multi-level, integrative inquiry is particularly related to prevention efforts and chronic disease management, which might be expressed as: *the smallest unit of meaning is the life of the whole person*. This is a tenent of the socio-ecological approach to health and well-being. The methodology here includes attention to the contextual organizational influence on communication at the individual level, and therefore may provide a more complete account of communication and experience that occurs during primary care interactions. A focus is on explicit and implicit communication –the contextual significance of emotional and instrumental talk – and exploratory critical discourse analysis of conflicts, tensions and ideals that emerge therein.

Additionally, relationships between patients and health care providers cannot be described adequately using analyses of interactions between them. This research emphasizes the need to triangulate between these objectively coded observations and the participant perspectives in order to understand what makes for authentic relationship-centered care. Results, discussion, and lessons learned from the research approach used here may help inform future inquiry into the factors and impact of critical contextual review of quality communication in the primary care setting. One of the defining features of primary care, which represents the largest per capita source

of medical visits in the United States (Edwards, Mafi, & Landon, 2014), is that it is continuous, especially considering the political and institutional push for care coordination with a primary care medical home as the foci of primary relational interaction. Although patients may experience episodes of illness from time to time, it is assumed that a continuous relationship with one's own health care provider adds value and reduces the costs of care over time (Koopman, Mainous, Baker, Gill, & Gilbert, 2003; Tarrant, Dixon-Woods, Colman, & Stokes, 2010). For example, utilizing the emergency room for one's primary care as poor and uninsured in some communities are forced to do, is considerably more expensive than having a clinic or a primary care provider as a reliable source of care (Friedberg MW, Schneider EC, Rosenthal MB, Volpp KG,Werner RM, 2014; O'Toole et al., 2010; Weinberger, Oddone, Henderson, & The Veterans Affairs Cooperative Study Group on Primary Care and Hospital Readmission, 1996). Despite the assumption that continuity of care adds value to the processes and outcomes of care, there are almost no longitudinal studies of communication between physicians and patients, and certainly none with a sample size large enough to generalize regarding variance among populations of patients within large health systems. Refining methodological approaches which move towards capturing and analyzing real-time relational interactions will go a long way in resolving this issue, and research methods such as the one undertaken here may serve to inform those approaches.

The lessons from this approach may have implications for teaching and practice, too. This research took place in primary care offices within a community academic teaching hospital system. Elements of this research can be defined as an exploratory feasibility study. The methodology proposed here was the first

undertaking of such research in the clinical setting at the participating family medicine department. There was a functional objective goal of this research to help inform the curricula and didactic approaches to patient-centered care in the family medicine residency program run by faculty at these practices. It is assumed that the clinical skills needed to improve these problems can be taught and the subsequent benefits to medical practice are therefore demonstrable, feasible on a routine basis, and enduring. Therefore a clear and urgent need for encouraging, developing, and sustaining these inter-personal clinical skills in medical school curriculums, postgraduate training, and continuing medical education is evident and needed. Practitioners' talk with patients will be evaluated very differently depending on whether it is compared with currently influential views of the importance of relationship centered care or with what the practitioners intend and with what their patients experience at the time, something to which this study may contribute, both theoretically and practically.

Finally, there may be an important opportunity for stimulating organizational and community-level engagement and outreach with the results of this inquiry. Aligning patient-level expectations and goals for relationship-centered care delivery within the communities in which patients live; with institutional goals on patient-centered medical home implementation under a health reform dynamic is a critical component of aligning care practices towards value-oriented outcomes. This level of engagement may help to clarify individual expectations, address appropriate gaps in communication and outreach, and create more valuable institutional relationships within the context of a supportive, responsive and integrative primary care and community health infrastructure.

**Definitions of Terminology**

Key Definitions of Terminology used in this dissertation may not be familiar to all readers. Definitions of terminology, and associated acronyms, represent common use within the framework of the research that was conducted for this dissertation and many are presented in various figures and tables throughout this work. A full listing of key definitions of terms used throughout this dissertation may be found in Appendix E: Definitions of Terminology. Many of the terms defined are explored in more depth throughout Chapter 2 in the review of literature.

**Chapter 2**

**REVIEW OF THE LITERATURE**

**Overview**

*"All systems of classification are perceptual, artificial and arbitrary.*

*Whose definitions prevail at any given time and place*

*is a matter of politics, persuasion and preference."*

-- Michael Patton, A Vision of Evaluation that Strengthens Democracy (2002)

This chapter synthesizes and places into context the theoretical, conceptual and empirical literature informing this research project. I begin with identifying and defining (as clearly as possible) the key terms and concepts used in the formulation of this research and follow by contextualizing the most pertinent, encompassing and up-to-date literature relating the concepts in reference to this dissertation. This review of the literature is formatted to describe these formative and summative elements in a manner reflective of my theoretical approach to analysis and synthesis information by organizing the literature into three major areas of focus: *antecedents for change at the system level, antecedents for change at the organizational or team level,* and *antecedents for change at the individual level*. The review of literature is structured in this manner to lay the groundwork for a critical approach to analysis and synthesis of macro, meso, and micro-level data.

Of note, many of the terms, such a "patient-centeredness", described in this section do not retain a clear or agreed-upon definition among the available data in the

literature. This is to be expected given the exploratory nature of this research and this remains the point in affirming the empirical need for a more integrated inquiry, including a systematic critical approach to both methodological and analytical goals when engaging research topics such a patient-centered care.

<div align="center">**Antecedents at the System Level**</div>

<div align="center">*Primary Care Delivery System in the United States*</div>

The current institutional and systems-level organization of health care infrastructure in the United States consistently results in a level of spending that fails to translate into delivery of high-quality, high value health care. This often contributes to inequity in health outcomes across populations, leading to disparities within sub-groups of marginalized and disenfranchised citizens (E. Fisher, Goodman, Skinner, & Bronner, 2012; Sutherland, Fisher, & Skinner, 2009; Weinstein & Skinner, 2010).

Achieving the triple aim of health reform—better health, improved patient experience, and more affordable costs—is dependent on a foundation of high-performing primary care (Berwick et al., 2008a; Davis, Abrams, & Stremikis, 2011; Valentijn, Schepman, Opheij, & Bruijnzeels, 2013). To this end, a vigorous movement is underway to re-engineer primary care practice towards a model which elicits patient-centered care.

One real influence of federal health care reform efforts is the reinforcement of strong primary care foundation designed to meet the majority of preventive, acute, and chronic health care needs of its population. However, the recent challenges facing health care in the United States have been particularly magnified within the primary care environment. For example, inequity in suitable and reliably consistent access to

primary care is limited geographically in many areas, particularly within rural

communities as well as economically and socially disparate tracts of low-income

urban communities (Petterson et al., 2012). Furthermore, fewer U.S. physicians are

choosing primary care as a profession and satisfaction among primary care physicians

has waned amid the growing demands of maintaining, let alone growing, an office-

based practice (Gray, Stockley, & Zuckerman, 2012). Because of these reasons and

others, there is a growing concern that current models of primary care delivery will not

be sustainable for meeting the broad, demanding, and often chronically complex

health care needs across diverse populations of Americans.

Consequently, a robust primary care sector has long been described as the

driving force of a more effective and efficient health care system (Gray et al., 2012; K.

L. White, Williams, & Greenberg, 1961; Yarnall, Pollak, Ostbye, Krause, &

Michener, 2003). Achieving a dynamic primary care sector which systematically

delivers evidence-based, patient centered care will require widespread practice

transformation and payment reform innovation, much of which is currently underway

as a consequence of federal health care delivery and payment reform.

In 1992, Barbara Starfield defined primary care as care that is characterized by

first contact, accessibility, longitudinality, and comprehensiveness (Starfield, 1992).

More recently, great attention has been paid to the notion of a "medical home" --

specifically, a patient-centered medical home (PCMH). A relative consensus of

practitioners, researchers, professional societies and organizations currently support

the patient-centered medical home model, proposed as joint principles by four major

primary care professional associations. This approach is now seen as the blueprint for

practice transformation in relation to reforms codified in elements of federal health

care legislation (Klein, Laugesen, & Liu, 2013; Peikes, Zutshi, Genevro, Parchman, & Meyers, 2012).

<p style="text-align: center;">*Family Medicine*</p>

Framing the forty-plus year history and progress of family medicine as a primary care specialty area needs to be done within the social context that influenced its creation. G. Gayle Stephens, the so called poet-laureate of family medicine, argues effectively that the eventual establishment of the organized family medicine was closely tied to the expectations that the public had for the people who provided their care (Stephens, 2010). Rooted in a rather activist atmosphere, Stephens understood that these expectations were not being met, and the answer to this dilemma was a new specialty that would train family doctors to become the patient-centered care providers the public desired. This reform ontology, aimed at transforming the patient care arena, is closely tied to the dialectical nature of social movements at the time and a cultural-historical influence on practice norms.

Family medicine as a specialty in the United States arose from a tradition of general family practitioners. The family physician's ability to care for an entire family through cycles of birth, childhood, adulthood and death is a unique charge in modern medicine (Glazer, 2007). Physicians who specialize in family medicine must successfully complete an accredited three-year family medicine residency in the United States in addition to their medical degree (American Academy of Family Physicians, 2001; A. K. David, 2007). Family medicine providers play a very important role in the U.S. health care system, attending to more than 208 million, or nearly one in four of all office visits each year (Edwards et al., 2014). The scope of this care provision accounts for nearly eighty-five million more office visits than the

next largest medical specialty (Edwards et al., 2014). America's traditionally underserved and rural populations receive more care from family medicine providers than from providers of any other medical specialty, preserving a long and proud history of advocacy for patients, community involvement and service (Green & Puffer, 2010). This service orientation, rooted in the family medicine specialty's opus, the Folsom Report, emphasizes the community as the natural habitat for family physicians, currently placing family medicine as a vector for upstream innovation in addressing socio-ecological determinants of health in an evolving health care environment (Folsom Group, 2012).

**Antecedents at the Organization and Team Level**

*The Patient Centered Medical Home*

The Patient-Centered Medical Home (PCMH) has been set forth as a promising model of medical practice redesign in the transformation of primary care delivery within the United States health care system. However, the complexity involved in implementing the PCMH model into primary care practice is quite challenging. Additionally, the concept of a patient-centered medical home (PCMH) has captured the imagination of many parties to the national debate on health care reform; PCMH is a prominent construct in many of the cost and quality elements of the Patient Protection and Affordable Care Act (Goodson, 2010). The American Academy of Pediatrics first used the term "Medical Home" in 1967 to describe the concept of a centralized source of care and medical record for children with special health care needs (Sia, Tonniges, Osterhus, & Taba, 2004a). Building on other widely

disseminated efforts, such as the chronic care model (Wagner, Austin, & Von Korff, 1996), the current concept of PCMH has been significantly scaled on the back of nearly forty years of previous efforts to redesign primary care to provide the highest quality and highest value of care possible (Carrier, Gourevitch, & Shah, 2009; Crabtree et al., 2011; Ferrante et al., 2010).

In 2007, four major medical societies, American Academy of Family Practitioners, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association, came together under a Patient-Centered Primary Care Collaborative (PCPCC) to establish the *Joint Principles of a Patient Centered Medical Home*. The PCPCC defines a patient centered medical home, in broad terms, as a physician-directed practice that provides care that is "accessible, continuous, comprehensive and coordinated and delivered in the context of family and community" (Patient-Centered Primary Care Collaborative, 2009). The publication of the Joint Principles encouraged movement to define the PCMH in more detail. Driving this effort was the willingness of some payers (both public and private insurers) to consider enhanced payments to practices meeting certain qualifications.

In 2008 the National Committee on Quality Assurance (NCQA) revealed a PCMH recognition process with specific requirements (Reid, Baxley, Stanek, & Newton, 2011). This recognition process and accreditation was revisited in 2011, and a revised process is expected in the summer of 2014. Some literature shows that primary care practices find PCMH standards useful for targeting specific improvement efforts aimed at optimizing reimbursement, but the recognition process has come under criticism in recent research (Friedberg MW, Schneider EC, Rosenthal MB, Volpp KG,Werner RM, 2014; Schwenk TL, 2014). Under the current design, primary

care practices may receive recognition without making real meaningful fundamental change and some feel that NCQA requirements are excessively prescriptive, using a checklist-type approach that is ultimately non-responsive to the needs of patients and unable to deliver on core elements of patient-centered care (Schwenk TL, 2014).

The current political and organizational interest in the patient centered medical home has derived from growing recognition that even patients who are traditionally described as socio-economically advantaged, with ample access to economic and social support resources like meaningful employment, health insurance, and a supportive community infrastructure, may not have an established source of access to basic primary care services. This reality often results in a non-coordinated fragmentation of care delivery which drives poor quality and high cost of care (Berenson et al., 2008a; Hofer, Abraham, & Moscovice, 2011; Kilo & Wasson, 2010).

Table 2. Historical Perspective of Primary Care Practice Redesign illustrates an historical look at important events, groups, and policies that have shaped the evolution primary care practice redesign towards a patient centered medical home model during the last five decades.

Table 2.      Historical Perspective of Primary Care Practice Redesign

| 1960–69 | |
|---|---|
| -Medical home named for ill children<br>-Problem-oriented medical record<br>-Electronic health record | -Primary care named and described<br>-Medicare and Medicaid<br>-Surgeon general—smoking & cancer<br>-Nurse practitioner; physician assistant |
| **1970-79** | |
| -North American Primary Care Research Group<br>-Society of General Internal Medicine<br>-Society for Medical Decision Making | -National Cancer Institute<br>-Managed care/HMO<br>-National Institute on Aging<br>-Veterans Affairs ambulatory care programs |
| **1980–89** | |
| -Primary care practice–based research<br>-Agency for Health Care Policy and Research (AHCPR) | -Picker Institute<br>-U.S. Preventive Services Task Force |
| **1990–99** | |
| -Institute for Healthcare Improvement<br>-Idealized Design of the Clinical Office Practice<br>-Chronic Care Model<br>-Clinical Microsystems | -OBRA 1993<br>-Resource-based relative value scale (RBRVS) fee-for-service<br>-Social Determinants of Health model<br>-Hospitalists named and described<br>-Tobacco settlement - Prevention |
| **2000–PRESENT** | |
| -American Academy of Family Physicians promotes medical home<br>-Institute of Medicine Quality Report<br>-Joint principles of the PCMH<br>-Medical home demonstrations | -Medicare Part D<br>-PPACA 2010<br>-CMS Innovation Awards<br>-PCORI (Patient Centered Outcomes) |

Note. Adapted From Kilo & Wasson (2010, p. 774).


The timeline and associated activities presented in Table 2 illustrates how influential stakeholder groups, policy leaders, and health services research efforts have brought the patient centered medical home to the forefront of current primary care practice. Embedded within this evolution is the underlying assertion that patients thrive best when care is centered on their knowledge, attitudes, beliefs, and goals.

*Patient-Centered Care Delivery Models*

Clinicians recognize the importance of assessing and engaging patient context in making clinical recommendations (Mishler, 1984). However, the literature is consistent that patient-centeredness in the clinical setting is rarely approached in a systematic and coherent way that considers the full breadth of the patient's life circumstances (C. A. Barry, Stevenson, Britten, Barber, & Bradley, 2001; Becker et al., 2010; Bertakis et al., 2009; Hall, Roter, & Katz, 1988; Katz & Capron, 2002; Stange et al., 1998; Tai-Seale, Bramson, & Bao, 2007). While physicians are trained to assess a patient's clinical state (from the history of present illness, physical exam, laboratory, and other tests), their preferences (values), and the research evidence (through a critical appraisal of the literature), integrating patient context into health care decisions remains an element of what the evidence-based medicine literature calls "clinical expertise" (Haynes, Devereaux, & Guyatt, 2002). The following care delivery models have come to dominate the theoretical underpinnings of primary care delivery. In many ways, they are iterative examples of a continuing dynamic towards models of care delivery that emphasize relationship as the core driver of therapeutic outcomes.

Wagner and colleagues' chronic care model (Wagner et al., 2001) introduced the conceptual grounding for research that showed positive clinical outcomes are the result of an informed and engaged patient who believes that his or her role as a patient is vital to optimizing outcomes. Care delivered under this construct relies on a patient who has the confidence and knowledge necessary to take action, and who enacts behaviors to maintain and improve his or her health, even under biomedical and psychosocial stress (Hibbard, Greene, & Tusler, 2009; Wagner et al., 1996). Within a primary care setting, this framework seeks to organize an approach to caring for

chronically ill patients, such as diabetics, who often follow complex treatment regimens, monitor their conditions, and make lifestyle changes according to a deliberative therapeutic alliance with their health care provider (Attale et al., 2010; Coleman, Austin, Brach, & Wagner, 2009). The Chronic Care Model was among the first integrative models of primary care delivery to acknowledge the multi-level influence of socio-ecological structures on individual's ability to managed chronic disease.

In the 1950s American humanistic psychologist Carl R. Rogers developed the concept of client-centered therapy (Rogers, 1946; Rogers, 1966). This approach was promoted in the health field by psychoanalyst Michael Balint, who introduced the term "patient-centered medicine" into practice (Balint, 1957; Balint, 1984; C. A. Barry, Bradley, Britten, Stevenson, & Barber, 2000). Today, patient-centered care is widely acknowledged as a core value in the delivery of primary care within a patient centered medical home (Wagner et al., 1996; World Health Organization, 2001). Models of care delivery rooted in patient centered care have been associated with a variety of positive outcomes: reduction of malpractice complaints and improvements in physician satisfaction, consultation time, patients' emotional state, and medication adherence (O'Leary, Darling, Rauworth, & Williams, 2013; M. A. Stewart, 1984; M. A. Stewart, 1995; Street Jr., 2013). Care delivery models based on patient-centered care also have also shown to increase patient satisfaction and empowerment, as well as reduce symptom severity, use of health care resources, and health care costs (Bertakis & Azari, 2011; Cosgrove et al., 2013; Miles & Mezzich, 2011).

Moira Stewart, who is a stalwart investigator into patient-centeredness, described the patient centered care model in her seminal 2003 work, *Patient-centered*

*medicine: transforming the clinical method,* which built on her prior work and on which she continues to develop (M. Stewart, 2001; M. Stewart, 2003; M. A. Stewart, 1984; M. A. Stewart, 1995). Stewart is now one of the most mentioned investigators in primary care and family medicine research and much patient-centered care evidence in primary care family medicine relies on Stewart et al.'s research and practical modeling for patient centered care. Stewart was among the first to systematically approach the limitations to defining patient centered care by initiating inquiry into crucial questions about patient centered medicine: *What is it? Do patients want it? Do doctors practice it?* and of course *What are its benefits?*(M. Stewart, 2001; M. Stewart, 2003). The model she proposes based on her extensive research includes six dimensions: (1) exploring both the disease and the illness experience; (2) understanding the whole person; (3) finding common ground; (4) incorporating prevention and health promotion; (5) enhancing the patient–physician relationship and (6) being realistic. A model of patient centered care in clinical interactions which reflects Stewart's work is represented in Figure 3. Model of Patient-Centered Care with elements adapted from Moira Stewart's work spanning from 1984 through 2003 (M. Stewart, 1984; M. Stewart, 2001; M. Stewart, 2003).
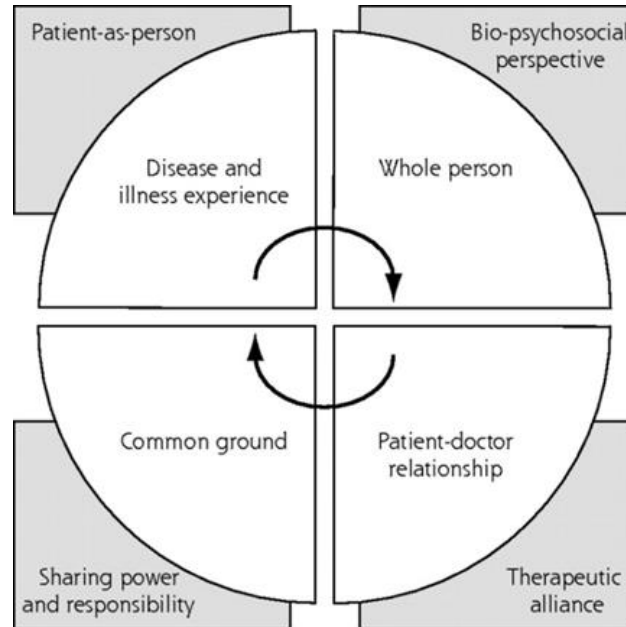
Note. Adapted From Stewart (1984), Stewart (2001) and Stewart (2003).

Figure 3.      Model of Patient-Centered Care

## Antecedents at the Individual Level

### *Patient-Centered Care*

The phrase "patient-centered care" is in vogue but its meaning is poorly understood, both conceptually and pragmatically.  The literature on patient-centered care extends across a broad range of topics, including physician communication, training, health information technology, the built environment (the spaces and products in health care facilities), and strategies for measuring and comparing approaches to patient-centeredness (A. David, Baxley, & ADFM, 2011; Frankel et al., 2011; Laine & Davidoff, 1996; Levinson, Lesser, & Epstein, 2010b; Rodriguez et al.,

2008; Starfield, 2011). Moreover, the health care provider and his or team is often constrained in their ability to provide patient-centered care by the context in which they operate, whether it be within a large hospital system, small community practice, franchised urgent care facility, or clinically integrated multidisciplinary group practice (Greene, Tuzzio, & Cherkin, 2012).

Since 1988, when the Picker/Commonwealth Program for Patient-Centered Care (now the Picker Institute) coined the term "patient-centered care", there has been a fervent call for attention to the need for clinicians, staff, and health care systems to shift their focus away from disease-centric care and back to the patient and family (Gerteis et al., 1993; Hart, 2010; Jenkinson, Coulter, Bruster, Richards, & Chandola, 2002). Patient-centered care describes a care delivery model designed to stress the importance of better understanding the experience of illness and of addressing patients' needs within an increasingly complex and fragmented health care delivery system.

In partnership with patients and their families, the Picker Institute conducted a multi-year research project centered on identifying critical elements of patient-centered care (Gerteis et al., 1993). Eight characteristics of care, from the perspective of patients, were identified as the most important indicators of quality and safety:

1. respect for the patient's values, preferences, and expressed needs
2. coordinated and integrated care
3. clear, high-quality information and education for the patient and family
4. physical comfort, including pain management
5. emotional support and alleviation of fear and anxiety
6. involvement of family members and friends, as appropriate
7. continuity, including through care-site transitions
8. access to care (p.11)

Although the phrase "patient-centered care" was coined several decades ago, it entered the health policy lexicon in 2001, when it was featured prominently as one of the six aims for high-quality health care in the landmark report from the Institute of Medicine (IOM), *Crossing the Quality Chasm* (Berwick, 2002; Institute of Medicine, 2001). Furthermore, recent advocacy for the patient-centered medical home has focused renewed attention on the phrase (R. M. Epstein & Street, 2011a; R. M. Epstein & Street, 2011c; Landon, Gill, Antonelli, & Rich, 2010; Sia, Tonniges, Osterhus, & Taba, 2004b; Stange et al., 2010) and organizations such as the Commonwealth Fund and the Society for General Internal Medicine have proposed steps to achieve such care (Blue Ribbon Panel of the Society of General Internal Medicine, 2007; Fund, 2011). But many in the health policy community do not have a good understanding of what "patient-centered care" means, or even why it matters within a value-oriented framework of health care delivery and outcomes. (R. M. Epstein & Street, 2011c; Nutting et al., 2009; Saha, Beach, & Cooper, 2008a).

Patient-centered care is often defined by what it is not—namely, disease-centered, technology-centered, physician-centered, or hospital-centered care (Levinson, 2011). Patient-centered care, likewise, is not simply ceding to patients' requests, nor is it throwing information at people and leaving them to sort out jargon, prescription instructions, and recommendations on their own. The IOM's Quality Chasm report defined patient-centered care as care that is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001). These attributes are more than just desirable. They are critical to providing the right care for the right person at the right time—a goal that has significantly important cost, quality

and policy implications, particularly in the current healthcare environment (Friedberg, Hussey, & Schneider, 2010).

In the traditional sense, patient-centered care derives from the healing relationships between clinicians and patients and, by extension, patients' family members (Berenson et al., 2008b). A patient-centered approach fosters interactions in which clinicians and patients engage in two-way sharing of information; explore patients' values and preferences; help patients and their families make clinical decisions; facilitate access to appropriate care; and enable patients to follow through with often difficult behavioral changes needed to maintain or improve health (Holmstrom & Roing, 2010). Patient-centered care also aims to improve clinical practice by building caring relationships that bridge demographic, social, and economic differences between clinicians and patients (Kaplan, Sheldon Greenfield, & Ware, 1989; Levinson, 2011). Within this context, patient-centered care has resulted in improved care processes (Greenfield, Ware Jr, Yano, & Frank, 1988) and health outcomes, including survival (Meterko, Wright, Lin, Lowy, & Cleary, 2010). Two systematic reviews identified promising patient-centered interventions directed at patients, clinicians, or both, which resulted in improved communication and health outcomes (Griffin et al., 2004; Rao, Anderson, Inui, & Frankel, 2007).

*Relationship Centered Care*

The conceptual trajectory of patient centered care leads next to relationship centered care. The literature on primary care-oriented health systems assumes that one of the mechanisms for optimizing beneficial health outcomes results from a greater focus on patients as they transition from one health problem to another (Starfield, Shi, & Macinko, 2005b). Conceptually, primary care is designed to be practiced in the

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context of person-focused, not disease-focused, care over time (Khan, 2008). To be person-focused, primary care must be accessible, comprehensive (dealing with all problems except those too uncommon to maintain competence), continuous over time, and coordinating when patients have to receive care elsewhere (Starfield, 1992; Starfield, 2011). The principle of person focus infers a focus on time, coordination and trajectory rather than a focus on episodic, iterative interface. Necessarily, this extends beyond communication because much of it relies on knowledge of the patient (and of the population of potential patients) that accrues over time and is not specific to disease-oriented episodes as well as the transfer of knowledge and knowledge commodities that may serve to enhance or deteriorate health over time. Ultimately, providers and patients working together to reach agreed upon decisions, goals, and outcomes will require a long-standing relationship built on trust and reciprocity (Kon, 2010).

In 1994, a group of renowned social and clinical researchers, educators, and health care practitioners produced a landmark report affirming the fundamental significance of relationships in health care (Tresolini & Pew-Fetzer Task Force, 1994). Their work highlights the theory and evidence supporting the impact of relationships between patients and clinicians; among members of interdisciplinary health care teams; between the health care system and the community; and—especially noteworthy—the relationship of the clinician with her or himself (Frankel, 2004; Mauksch, Dugdale, Dodson, & Epstein, 2008; Tresolini & Pew-Fetzer Task Force, 1994). The concept that they introduced, relationship-centered care (RCC), represents the progression in a long-standing movement to advance humanism in medicine -- to complement the objectivist and reductionist approach of science-based practice with a

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compassionate, relational approach to the patient's subjective or lived experience of health and illness along the life-course (Beach & Inui, 2006; Weisz, 1998). This relational model of care is theory driven and prescriptive in nature, and based on four major principles: (a) relationships in health care ought to include dimensions of personhood as well as roles of all actors at the level of health care; (b) affect and emotions are important components of relationships in health care; (c) all relationships occur in the context of reciprocal influence. Thus, the smallest unit of measurement in this method is an interactional dialog at the personal level; and (d) relationship-centered care has a moral foundation that drives behavioral approaches. This characterizes an added element to the agenda of RCC's immediate precursors, the chronic care model, the patient-centered care model and the Biopsychosocial Model (Borrell-Carrió, Suchman, & Epstein, 2004; Engel, 1980; McWhinney, 1972; M. Stewart, 2003).

Advancing the philosophy of person centered engagement in care; the Relationship Centered Care takes another step forward by calling attention to the personhood of the clinician as well as that of the patient. It also recognizes explicitly the emergent capacities of a partnership or team to do things together that the individuals could not do on their own. According to the advocates of RCC, the capacity to form effective relationships and capacity for self-reflection are essential to good clinical care, and should be developed as a part of medical education (Beach & Inui, 2006; Cooper, Beach, Johnson, & Inui, 2006; Entwistle & Watt, 2013). This theory driven approach lays the groundwork for converging theoretical and practical inquiry into patient centered communication, which is the basis for the research proposed here.

*Patient-Centered Communication*

Communication and relationship have long been understood as important in the delivery of effective health care. For example, Stanley Reiser, in his 1980 work titled, "Words as scalpels: Transmitting evidence in the clinical dialogue", noted that early Greek physicians such as Plato warned that telling bad news to patients should be avoided because it could worsen their condition (Reiser, 1980). This view of avoiding certain types of communication continued into the modern era and was reflected in the first code of medical ethics adopted by the American Medical Association (AMA) in 1847, which stated, "It is a sacred duty [of a physician] to avoid all things which have a tendency to discourage the patient and depress his spirits" (American Medical Association, 1996). Although the practical and ethical nature of non-disclosure is debatable, the sentiment in the statement above is rooted in empathy. Studies and literature reviews in the decades since confirm the effect and importance of this relational communication in the medical encounter (R. Baker, 1999; Bohlen, Scoville, Shippee, May, & Montori, 2012; Buckman, 1992; Deledda et al., 2013; Mauksch et al., 2008; Oken, 1961; Ridd, Shaw, Lewis, & Salisbury, 2009).

The "patient centered" communication movement began to transform the paradigm of care delivery in the 1970s. Lipkin et al in 1984 defined it as treating the patient "as a unique human being with his own story to tell" (Lipkin, Quill, & Napodano, 1984). Many other health services researchers, practitioners, and social scientists have since proposed meanings, definitions and criteria for patient centeredness, as recently reviewed by Saha, and colleagues (Bensing et al., 2013; Bernabeo & Holmboe, 2013; Deledda et al., 2013; Deledda et al., 2013; Saha, Beach, & Cooper, 2008b). For example, Epstein (2005) proposes that patient-centered communication must include:

1.  Eliciting and understanding the patient's perspective – concerns, ideas, expectations, needs, feelings and functioning.
2.  Understanding the patient within his or her unique psychosocial context.
3.  Reaching a shared understanding of the problem and its treatment …
4.  Helping patients to share power and responsibility … (p. 1517)

In 2010, the Joint Commission, an independent, not-for-profit organization which accredits and certifies more than 20,000 health care organizations and programs in the United States,  released a set of revised standards for patient-centered communication as part of an initiative to advance effective communication, cultural competence, and patient- and family-centered care. These standards are designed to improve the safety and quality of care for all patients and to inspire hospitals to adopt practices promoting better communication and patient engagement (Joint Commission, 2010). Although the majority of these guidelines represent administrative components related to more contextual data collection than is traditionally gathered, The Joint Commission is continually urging hospitals to integrate concepts from the communication, cultural competence, and patient- and family-centered care fields into their organizations.

Plausibly, achieving patient centered communication ideals would require more time than interactions centered purely on bio-medical issues, as framed and directed by the physician. As Epstein and colleagues discuss further in subsequent research and analysis, however, there is no consensus about how to meaningfully measure patient-centeredness, and limited evidence points to a gradient of causality as to how its various components are related to outcomes (R. M. Epstein, Fiscella, Lesser, & Stange, 2010a; R. M. Epstein & Street, 2011a).

Describing effective elements of patient-provider communication has been a holy-grail of sorts among health care advocates, researchers, administrators, and practitioners. Explaining how and why communication contributes to health outcomes requires a deeper understanding of how specific, well-defined aspects of communication are linked to specific outcomes, as well as an understanding of how contextual factors – within the clinical setting as well as family and social factors extrinsic to the clinical setting – enrich or impoverish the effects of communication on health (Street Jr, Makoul, Arora, & Epstein, 2009; van den Eertwegh, van Dulmen, van Dalen, Scherpbier, & van der Vleuten, Cees PM, 2012; Wolff et al., 2012). This requires that investigators move beyond descriptive conceptual frameworks to formulate theoretical explanations linking communication to health. Moreover, researchers must also distinguish shared values defined by outcomes, especially those related chronic diseases and encounters in the primary care setting, that are less influenced by an episodic patient-provider encounters, and more the result related to the cumulative effect of the patient's communication over time with their personal physician, other health care providers, families, and friends (Gudzune, Clark, Appel, & Bennett, 2012; Hoerger et al., 2013; Street Jr., 2013; Thornton, Powe, Roter, & Cooper, 2011a).

*Engagement*

Although the term "patient engagement" is commonly used in discussion about meaningful patient involvement in health care initiatives, the term is often defined numerous ways throughout the literature. There is a lack of common language, terms, and definitions when referring to the concept or practice of patient engagement and also as it relates to interpretation of the term by stakeholders (Gruman et al., 2010).

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Defining "engagement" is not an easy or clear exercise and this issue is often recognized in policy and advocacy development when discussing the concept of citizen engagement where the lines between citizen involvement, participation and engagement may be blurred (Kingdon, 2002; Minkler, 2005; Sheedy, MacKinnon, Pitre, & Watling, 2008). A framework that takes these issues into account emphasizes the need to address effective patient-centered care from multiple levels of understanding and action. This approach informs the inquiry in this dissertation and is reflective of the integrative methodology used in this research.

Kristen Carman and colleagues recently proposed a multi-dimensional framework for patient and family engagement in health and health care, which emphasizes engagement across a spectrum of interaction, as presented in Figure 4. Multi-Dimensional Framework for Patient Engagement.

| Engagement Level | Consultation | Involvement | Partnership |
|---|---|---|---|
| Individual Interaction | Diagnosis is made. Information is shared | Patients are asked about preferences for treatment plan | Treatment decisions made on patient preference, evidence, clinical judgment |
| Organizational Governance | Surveys about patient satisfaction and experience | Setting-based patient advisory councils. Patient Involvement | Patients co-lead quality and safety initiatives |
| Policy and Political Environment | Focus groups with patients. Opinions about health care | Patients' recommend research priorities & funding | Patients have equal representation, agency and power in setting agenda |

**Factors Influencing Engagement**
- Patient – Beliefs about role, health literacy, activation, education
- Organization – Policies, practices, culture, team dynamics
- Society – Norms, regulations, policies, inequity

Note. Adapted From Carman et al. (2013, p. 225).

Figure 4.    Multi-Dimensional Framework for Patient Engagement

The first level of engagement which Carman describes is direct patient care, where patients get information about a condition and answer questions about their preferences for treatment. This form of engagement allows patients and providers to make decisions based on the medical evidence, patients' preferences, and clinical judgment. In the second level of engagement, organizational design and governance, health care organizations reach out for consumer input to ensure that they will be as responsive as possible to patients' needs. In the third level, policy making, consumers

are involved in the decisions that communities and society make about policies, laws, and regulations in public health and health care (Carman et al., 2013).

*Shared Decision Making*

Decision aides are often used in the context of primary care delivery as a mechanism to help standardize patient centered approaches to care delivery. According to the latest systematic Cochrane review of 86 trials published through 2011(Stacey et al., 2011), the use of patient decision aids for a range of preference-sensitive decisions led to increased knowledge, more accurate risk perceptions, a greater number of decisions consistent with patients' values, a reduced level of internal decisional conflict for patients, and fewer patients remaining passive or undecided. These shared results regarding decision aides being used in patient centered care are consistent with more recent studies spanning the current, accepted definitions of shared decision making in primary and specialty care (Bernabeo & Holmboe, 2013; R. M. Epstein & Street, 2011b; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Politi, Lewis, & Frosch, 2013; Thorne, Oliffe, & Stajduhar, 2013).

Although there currently lacks a single standard definition of Shared Decision Making (SDM), it quite often conceptualized as a practice by which a healthcare choice is made by clinicians in partnership with the patient (Clayman & Makoul, 2009; Moumjid, Gafni, Bremond, & Carrère, 2007). Researchers and Shared Decision Making advocates often position SDM to be the crux of patient-centered care (Towle & Godolphin, 1999; Weston, 2001). A recent systematic review of SDM as an applied concept in care delivery settings identified one hundred and sixty one conceptual definitions and summarized the key elements in one integrative model of SDM in medical encounters (Makoul & Clayman, 2006b). However, none of the identified

definitions or the proposed models included an interprofessional or interpersonal perspective. The authors of this systematic review concluded that it was "equally important to study communication and decision-making in relatively mundane contexts such as primary health care," suggesting that SDM in primary health care contexts had not been addressed to evidentiary satisfaction (Légaré et al., 2011; Makoul & Clayman, 2006b).

Currently, existing literature points to a lack of direction in how the existing conceptual models, theories, and measurement tools used in the application of shared decision making and inter-professionalism relate to enhancing current practice, applied health services research, and training activities to support an integrative, coherent, and theoretically standard approach to shared decision making within a patient-centered model care delivery within the primary care setting. This research aims to identify elements of quality patient-provider communication that can inform this direction and help ease transition of decision aids into patient-centered practice guidance in medical home settings.

## Summary

There is hope that primary care physician practices, serving as patient centered medical homes, can bring some order to the chaos described in the beginning of this section. The goals of patient centered medical home models are designed to provide a source of confidence, advocacy, and coordination for patients as they encounter the disconnected parts and often daunting complexity of the modern health care system (Kocher, Emanuel, & DeParle, 2010). However various PCMH advocates and promoters have different, although not inconsistent, expectations and emphases and

definitions regarding patient-centeredness. For some, the concept relates mostly to the "patient-centered" component; for others, the most salient characteristics are found in improving the "systemness" of care, aided by new health information technology (HIT) and organizational structures; while still others emphasize chronic care and disease management. Ultimately, these emphases are not mutually exclusive and elements of each are dynamic and necessary for successfully meeting reform challenges. Within the context of the various expectations and definitions described briefly above, only when we develop alignment of vision can we begin to align definitions, goals, and the resources needed to achieve the far reaching ambitions of Don Berwick's "Triple Aim".

Thus, when the goals and objectives of patient centered care are practiced in the care delivery setting, clinicians come to know and respect patients' values, beliefs, hopes, and ways of dealing with adversity in addition to patients' clinical symptoms and concerns. In this context, clinicians can work to provide personalized care that is in alignment with the needs of a particular patient, hopefully meeting the needs of that patient in a manner that produces beneficial outcomes (Levinson & Shojania, 2011; Luxford, Safran, & Delbanco, 2011). Within this framework, clinicians know the patient's family circumstances and cultural norms well enough to help him or her with decisions about care, adherence to treatment regimens, and self-management to promote healing and prevent illness. Unfortunately, the traditional arrangement of healthcare often neglects these fundamental aspects of patient centeredness and it is uncertain if current efforts to address these issues, including certifying Patient Centered Medical Homes, are adequately meeting patient needs (Aboumatar, 2013; Waitzkin, 1991b).

## Conceptual Framework

The growing demands for quality, value and efficacy in health care have refocused attention on patient outcomes, even if efforts to ensure more consistently positive outcomes sometimes reduce the health care provider's prized autonomy. More than a century ago, Rudolf Virchow noted that medicine is intrinsically a social science, and politics nothing more than medicine on a larger scale (Virchow, 1958). Now, within a contentious political ecology, grave concern about the excessive and growing price of medical care in the United States has led to considerations of whether shifting care from the subspecialist to the primary care physician could reduce its cost. Thus, the patient-centered medical home is positioned, in both theory and practice, to reinstate the primary care provider(s) as the main locus of health care provision given it can deliver on such promise as longitudinal personal care, access to on-demand quality services, coordination among health care delivery services, home-based and social services, open medical records, pay for performance, and a functioning interoperable communications infrastructure.

Patient-centered communication is constructed by two social actors working within an activity system (a patient centered medical home) in order to create an activity (shared decision making) modeled along a pathway towards an agreed upon goal or outcome. The long-term outcome built around the sum of patient-centered communication activity during the visit is presumably directed at improvement in patient health outcomes. A model of this patient-centered communication activity is presented in Figure 5. Patient-Centered Communication Activity.
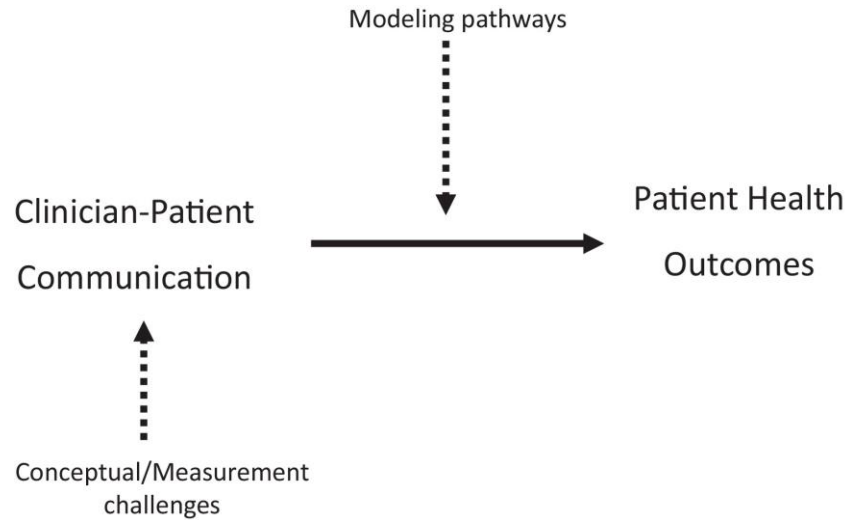
Note. Adapted From Street & Millay (2001).

Figure 5.    Patient-Centered Communication Activity

For the integrative approach that I utilized in this research, it is important to position this pathway-modeling of patient-centered communication within a social framework that allows for multi-level analysis. I place the patient-centered communication activity within a cultural-historical activity theory framework that might account for micro and macro elements of influence such as team-based care in a patient-centered medical home, or technology use as part of the interaction. A graphical depiction of this structural arrangement is presented in Figure 6. Cultural Historical Activity Theory.

**Tools**
Physical objects and systems of symbols
(like language, mathematics) that people
use to accomplish the activity

**Motives**
Purposes, reasons
for the activity

**Subject**
Person or people engaged in
activity who are the focus of a
study on activity. The point of
view used to focus on the
activity.

Object
Immediate
goals of
activity

Outcome
Long-terms
goals of
activity

**Rules**
Laws, codes, conventions,
customs, and agreements
that people adhere to while
engaging in the activity

**Community:**
People and groups whose
knowledge, interests,
stakes, and goals shape
the activity

**Division of Labor**
How the work in the activity
is divided among
participants in the activity

Note. Adapted From Kain (2003) and Sannino (2011).

Figure 6.     Cultural Historical Activity Theory

Cultural Historical Activity Theory (CHAT) is proposed here as an integrated conceptual and methodological framework for understanding complex relationships between discourse, actions and community and how patient-centered care goals can be appropriated and sustained. In this arrangement, the subject of an activity system is the person or people who are directly participating in the activity of study. The subject provides a point of view for studying the activity. Motives direct the subject's activities and include the object of the activity, which is fairly immediate, and the longer term outcome. Tools are used by the subject, within the conventions shaped by rules, in order to accomplish objectives toward the achievement of intended outcomes.

Within both professional and academic research, there is a growing interest in practice-based learning, research, and theorizing as a means to improve team based practice such as that being advocated for within patient-centered medical homes. In employing middle-range practice-based theory as frameworks, participatory learners like family medicine residents can utilize a critical theoretical framework to begin (re)shaping patient-centered practices. In the realm of health care delivery within complex health care systems, conceptual frameworks like cultural-historical activity theory being employed in this research can help illuminate and the complexities of social practices like patient engagement and chronic disease management.

One benefit of using the activity theory model to analyze multidisciplinary professional practices is that the framework provides ways of using practice-based theory to reflect on previous, current, and anticipated practices, and the multilevel sociocultural, political-economic, and institutional contexts of one's field of practice. Additionally, this approach has use in developing new ideas about how to improve future practices by understanding inherent contradictions within systems of care.

# Chapter 3

## RESEARCH METHODOLOGY

### Study Sample

Participant recruitment was similar to Patton's purposeful convenience and snowball sampling methods (Patton, 2005). The goal with Patton's purposive sampling technique is not to seek representation (Patton, 1999). According to this sampling strategy, the selection of the participants is first and foremost based on their accessibility to the researcher and, subsequently, for their information rich contributions to the subject matter. A feature of snowball sampling is the anticipation that initial participants in the study can help channel the researcher to communicating with other potential participants should they feel comfortable doing so. Only participants who agreed to all stages of data collection were selected for participation.

Purposive sampling was used in the recruitment of twenty-eight family medicine residents for participation in this study. Recruitment not stratified for heterogeneity in regards to race, gender, age, ethnicity or years of medical residency Recruited residents consisted of the entire class of first year, second, year, and third year residents enrolled in the family medicine (FM) residency or the joint family medicine/emergency medicine (EM/FM) residency program. Fifteen family medicine residents (fifty-four percent) acknowledged interest to participate via phone and/or email conversation with the researcher and then subsequently signed informed consented to participate in the research project. Eight residents were female (fifty-three percent), and seven were male (forty-seven percent) and the majority of all

resident participants (sixty-three percent) were white. The average age of resident

participants was 30.13 years (Range: 25 - 42 years) with and residents had on average,

2.13 post graduate years of experience in the family medicine or joint family

medicine/emergency medicine residency program.

Resident participants consented to both phases of their involvement in the

research, video recording of patient encounters and follow-up video elicitation

interviews.

Representative demographics and characteristics of the resident participants

are shown in Table 3. Characteristics of Resident Participants

Table 3.      Characteristics of Resident Participants

| Resident N = 15 | Mean Age in Years (Range) | Mean Post Graduate Years (Range) | Residency Program | Interaction Site |
|---|---|---|---|---|
| Female, n = 8 (53%) | 31.1 (25 – 42) | 2.6 (2 – 4) | FM, n = 5 EM/FM, n = 3 | Suburban, n = 4 (80%) Urban, n = 5 (31.3%) |
| Male, n = 7 (47%) | 29 (25 – 32) | 1.6 (1 – 3) | FM, n = 4 EM/FM, n = 3 | Suburban, n = 1 (20%) Urban, n = 6 (68.8%) |

Purposive sampling was again utilized in the recruitment of potential patient

participants. Through selective query of the family medicine office's electronic

scheduling and electronic health record tools, patients that met the following criteria

were first identified for recruitment:

- Patient is older than 18 years of age
- Patient has a primary diagnosis of diabetes mellitus [Type II Diabetes]

- ICD-9 classification: 250.00 Diabetes Mellitus Without Mention Of Complication, Type II or unspecified type, not stated as uncontrolled.
- Patient's primary language of communication is English
- Patient has no psychosocial complications that would interfere with participation.

An initial sample of thirty-five primary care visits for eligible diabetic patients who had visits scheduled with consented resident physicians were identified among block schedules for all family medicine office visits during a three month period between December 15, 2013 and March 15, 2014. Patients scheduled for these visits were introduced to the research via telephone and invited to participate in the research. Initially, twenty-six patients (seventy-four percent) verbally consented to participate during the telephone introduction and were made aware that the researcher, or a research assistant, would meet with them immediately prior to their scheduled diabetic follow-up visit to obtain written consent and to answer any outstanding questions regarding the research. Ultimately, seventeen eligible patients (forty-nine percent) provided written consent to participate in the video and audio recorded visit. During one clinical exam, one patient requested the video and audio recording be turned off after consenting. Recorded data from this visit was deleted from record and not utilized in this research. Of the sixteen patients participating in this study, ten were female, six were male.

Representative demographics and characteristics of the patient participants are shown in Table 4. Characteristics of Patient Participants.

Table 4.      Characteristics of Patient Participants

| Patients N = 16 | Mean Age in years (Range) | Race/Ethnicity | Site of Interaction |
|---|---|---|---|
| Female, n = 9 (62.5%) | 52.2 (42 – 68) | White = 44.4% AA = 33.3% | Suburban, n = 4 (80%) Urban, n = 5 (31.3%) |
| Male, n = 7 (37.5%) | 44.6 (25 – 51) | White = 28.6% AA = 71.4% | Suburban, n = 1 (20%) Urban, n = 6 (68.8%) |

**Study Setting**

The study was conducted in two (one urban and one suburban) family medicine primary care offices in Wilmington, Delaware. Aggregate insurance payer mix among patients in these practices consist of approximately 29% Medicare, 24% Medicaid, 39% private insurance, and 8%-10% self-pay or no insurance. Practice coordinators and staff were aware of the study, but may not have been aware of the specific study objectives. Video equipment, capable of both video and audio recording, was installed in one exam room at each site.  Video and audio equipment is visibly mounted on the ceiling of the exam rooms in a manner where both patient and provider will most likely be in frame together during a typical primary care encounter. Visual representation (faces of participants are obscured to protect privacy) of the field of vision provided by the camera equipment at each site is presented as Figure 7. Camera View in Urban Primary Care Office, and Figure 8. Camera View in Suburban Primary Care Office. The location of the patient, the resident, and the electronic health record (EHR) are identified in the figures.
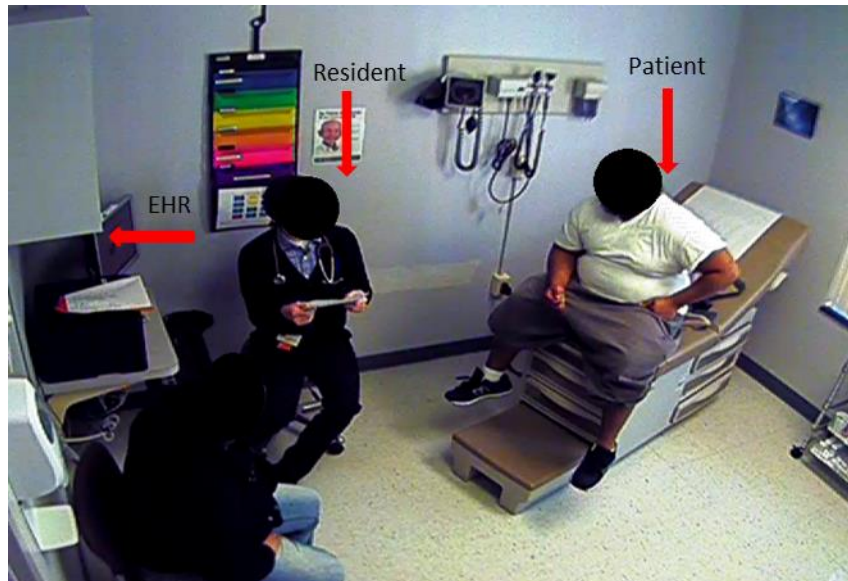
Figure 7.    Camera View in Urban Primary Care Exam Room
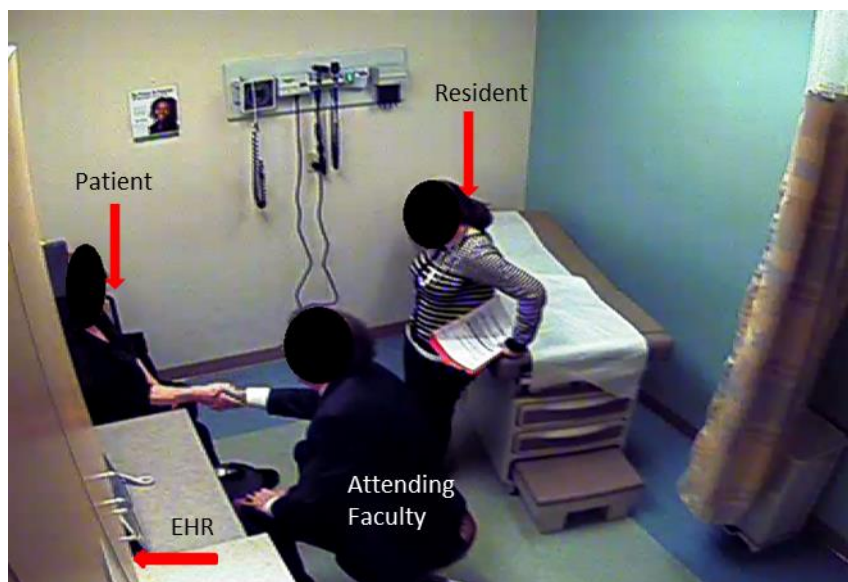


Figure 8.    Camera View in Suburban Primary Care Exam Room

These two practice offices are part of an academic-affiliated Family and Community Medicine department which is a primary care service line within a large, regional not-for-profit hospital system. The participating residents are employees of the hospital system. This family medicine primary care practice is currently accredited as a level I patient centered medical home by the National Committee for Quality Assurance (NCQA). This means the family medicine department has achieved operational standards for NCQA defined parameters related to Access and Communication, Patient Tracking and Registry Functions, Care Management, Patient Self-Management and Support, Electronic Prescribing, Test Tracking, Referral Tracking, Performance Reporting and Improvement, and Advanced Electronic Communication.

**Ethical Considerations**

The Institutional Review Board (IRB) at the hospital system has reviewed and approved this study on the basis that all identifiable patient and provider-specific data remain within the secure data infrastructure within the hospital system. A copy of the IRB approval is provided as Appendix A: Institutional Review Board Approval. Through a regulatory arrangement via the Delaware Health Sciences Alliance, the University of Delaware's Institutional Review Board approved this study for Human Subjects Research. A copy of the University of Delaware's IRB approval letter is provided as well in Appendix A.

Participating resident physicians and patients have provided informed consent as well as consent for digital audio and video recording. Participating patients and providers were informed that they were free to request that recording instruments be

turned off at any time. Audio recordings of video-elicitation interviews with residents were wiped after transcription, and transcripts were anonymized for removal of any identifiable protected health information.

A copy of the face sheet from the approved consent forms for residents and patients are represented in Appendix B: IRB Approved Consent Form Face Sheets. All participants were aware that the study focused on discussions between patients with diabetes and their health care providers but may not have been aware of specific study objectives.

## Methods

**Research Question 1**: *How is patient-centered care reflected in the observable interaction between family medicine primary care residents and diabetic patients within a primary care patient-centered medical home?*

In an effort to answer research question one, a micro-objective analysis of video and audio recorded interactions between patient and providers were conducted. Observable face-to-face interaction between the patient and resident physician dyad were situated as an organized unit of analysis. Within this cohort of audiovisual recorded/transcribed data, utterances were coded using a validated General Interaction Analysis System (GMIAS) methodology (Laws, Heckscher, Mayo, Li, & Wilson, 2004). This interaction analysis coding system is designed to capture various speech act concepts which have been used previously in health services and health communication research, as well as others such as patient expressive utterances (e.g. opinions, goals, affect) that are not captured by comparable coding systems. Unique in

relation to other established systems of coding speech acts and verbal interactions, the GMIAS assigns two codes to each utterance, one for topic, and one for interaction process (category).

A representation of the adapted GMIAS topics and categories used in the coding of the patient-provider interactions in this research is presented in Table 5.

Table 5.    Interaction Analysis Coding Categories

| General classification | Examples of specific sub-categories |
|---|---|
| *Speech act codes sub-codes* | |
| *Questions* | |
| Representative | Representative questions can be open, closed, leading |
| Expressive | Expressive questions can be open, closed, leading |
| Check understanding/knowledge | "Do you understand?" |
| *Representatives* | Statements about inter-subjective reality: General, own behavior, deduction, prediction |
| *Comprehension* | Statements of understanding or lack of understanding |
| *Expressives* | Values, opinions, desires, goals |
| *Emotions* | Affect, e.g. "I'm so sad about my mother's illness" |
| *Conversation Management* | Management of turn taking or visit agenda |
| *Empathy* | Expression of emotional rapport, support or reassurance ("That must have been difficult") |
| *Directives* | Recommend, mandate, encourage |
| *Commissives* | Promises, offers, permissions ("Okay, I'll set a quit date.") |
| *Jokes* | Intended humor that can be misleading if coded literally |
| *Social rituals* | e.g., ritual greeting and parting statements, "Excuse me," "Thank you." |
| *Missing* | Poor transcript quality prevents definitive coding |
| *Topic Codes and Sub-codes* | |
| *Biomedical* | Diagnosis, symptoms, tests, risk behaviors, and treatments |
| adherence | Adherence barriers, adherence problems |
| side effects | Specific side effects, concern about side effects |
| prescribing | Initiation of treatment or change in treatment plan |
| problem solving | Solving problems, overcoming barriers |

| General classification | Examples of specific sub-categories |
|---|---|
| *Psychosocial* | Substance abuse, recovery, emotions, relationships, health of others, family, social services, housing, well-being |
| *Logistics* | The "business" of the visit/appointment |
| Non physical exam | Appointments, referrals, electronic health record |
| Physical Exam | e.g., "Take a deep breath" |
| Socializing | e.g., "Did you see the ball game?" or "Is still raining?" |

The annotated coding manual utilized for this research may be found in Appendix C: Annotated Coding Manual for Interaction Analysis.

To identify the elements of patient-centeredness in a primary care interaction, the GMIAS was used in this research through the construction of five variables operationalizing previously used indicators of patient-centered care. A key component in standard definitions of patient centered care is "Eliciting and understanding the patient's perspective – concerns, ideas, expectations, needs, feelings and functioning." (R. M. Epstein et al., 2005; Greene et al., 2012). Representative of this standard definition, the variables used in addressing research question number one correspond to expressive speech acts, as coded in the GMIAS.

- The first measure of patient-centered communication is the fraction of all utterances which are *patient expressives*.

- The second measure is the proportion of all utterances which are within the *psychosocial topic*, including psychosocial context as part of common definitions of patient-centeredness.

- The third measure is physician verbal dominance – the *ratio of physician to patient utterances*. This measure was used in a seminal work which found that patient engagement in care – a concept similar to what would today be called patient-centeredness – associated with improved glycemic control among people with diabetes.

- The fourth measure is the *ratio of patient to physician questions*.
- The fifth measure is the *percent of patient utterances which are in the "control parameter."* In the interaction analysis coding system, these are questions, topic introductions and closures, directives, and commissives.

Next, the utterances coded as expressive speech acts were grouped into threads using a Comprehensive Assessment of Clinical Encounters methodology which was developed in relation to the GMIAS. The CASE system's unit of analysis is the thread, made up of processes, specific subject matter such as a symptom or complaint, medication adherence, or a psychosocial problem. Processes may originate from either the patient or the provider (Laws et al., 2013). Threads have ownership, either for the patient or the provider, and are made up of the following processes which correspond to generally accepted broad functions of clinical encounters: sharing information about the patient's condition and circumstances; providing health education and anticipatory guidance; making a diagnosis and deciding on treatment or otherwise meeting needs or solving problems; and providing reassurance and support.

Threads may be brief in nature, for example the resident may inquire if the diabetic patient has reduced her intake of sugar-sweetened beverages as they discussed at the last visit, six months prior, in response, the patient may answer affirmatively and the thread ends. Likewise, a thread may be lengthy, taking up any proportion of a visit in length. Threads will frequently reappear multiple times throughout the encounter. They may traverse multiple topic codes at the utterance level; the concept of the "subject" of a thread is different from that of topic categories. For example, a patient may mention pain in the upper back that produces headaches, which leads to discussion of other symptoms, psychosocial stressors, and potential remedies. Specific threads utilized in this study related to patient-centered communication are as follows:

- *Presentation*: The development of information about the patient's specific condition, symptoms, experiences or history.

- *Information*: Transfer of general information about the world, including the patient's conditions and treatments, which is not unique to the patient.

- *Engagement*:  Affective or relational exchange such as empathy, reassurance, or expression of feelings about the other party.

- *Resolution*: Discussion and decisions about how to respond to problems or issues such as prescribing, referrals, advice about self-management, or even a decision not to take action or a conclusion that nothing can be done.


The value of this nested coding approach (utterances within processes) to analyzing patient-provider interactions is that patterns of information flow may emerge more markedly when speech acts that are coded into different process are distinct from other processes, perhaps in ways that may have implications for elements of patient-centeredness such as engagement and shared decision making. It also provides a framework for contextualizing the use of information during a sequence of speech acts to develop an understanding of the dynamic process of clinical communication at the micro-level, and how this may produce delivery of patient-centered communication.

Coding of individual primary care office visits was done on transcribed data within QSR International's NVivo 9 software for qualitative data management (QSR International Pty Ltd., 2011). First, I observed audiovisual recordings of patient-provider interviews from the secure viewing software program (IndigoVision) associated with the video hardware installed in the clinic offices. I noted time (hh:mm:ss) of patient appointment, the time (hh:mm:ss) at which the consenting patient first entered the exam room, the time (hh:mm:ss) at which the consenting

resident entered the exam room (interaction begins), and the time (hh:mm:ss) when the patient or the resident exited the room, at which point the interaction ceased. I clipped the original audiovisual data to reflect the time from which the provider first entered the exam room until the time when the interaction ceased then imported the clipped audiovisual data pertaining to only the interaction between the consented parties into QSR International's NVivo 9 software.

In coding of individual patient-provider interactions, the textual transcripts of the interactions accompanied the audiovisual data within the detail screen pane of the NVivo software. Coding was performed within the text of the transcript while the video and audio was playing immediately adjacent to the text on the screen. This allowed me to pause, slow-down, and rewind the audiovisual content during the coding process but was very tedious in both time and attention.

Data management software utilized for this research was used primarily as a means to organize large amounts of data, not as a tool for shaping theoretical approaches or interpreting coding arrangements. Descriptive statistics, as well as non-parametric testing of speech acts, topics, and categories coded for patient-centered communication was completed using SPSS v.20 (IBM Corp., 2011).

**Research Question 2**: *What are the barriers and facilitators, from a provider perspective, to implementing patient-centered care within this setting?*

In answering research question two, a novel video-elicitation method to engage providers in a subjective analysis of their interpretations of the patient-provider interactions was utilized. Video-elicitation necessarily involves a process in which one or all of the participants, in this case the providers, view their video-recorded

interactions in a semi-structured interview format as a means for producing a participant-subjective account of the interaction (Henry & Fetters, 2012a).

The practical consideration for including this methodology is two-fold. First, encounter reviews by participating resident physicians may serve as "member-checking" (Christie & Alkin, 2008). In this sense, residents may become a participatory agent in establishing the trustworthiness of the data. To address this point specifically, during the video elicitation process, residents were asked to identify elements of their respective interactions that they perceived as being "patient-centered in nature". It is important to note that patient-centered as a concept, was not defined, taught or described to the residents in any specific manner prior to or during the elicitation process related to this research. This element of the elicitation process was recorded during the interview and was matched against time of coded patient-centered care elements.

As an exploratory exercise, Cohen's kappa coefficient was calculated for agreement of coded (by me) and elicited (by participating residents) elements of patient-centered care (Downe Wamboldt, 1992). Results are presented in Chapter 4.

Advantages of video elicitation include prompt recall of the kind of details for specific events, emotions, or thoughts that participants often either forget or misremember (Henry & Fetters, 2012a). Video elicitation is especially valuable when attempting to generate "thick" data on the subject's emotional life, taboos, or the strength of social bonds. Another advantage is that the stimulus in video elicitation can be a natural interaction as opposed to being acted. This has particular importance when eliciting emotion or studying empathy, although these are not explicit topics being studied here. Understanding residents' perceptions and intentions during clinical

interactions may clarify the links between deliberative (micro-objective) and heuristic (micro-subjective) strategies related to patient-centered care. In this case, etic analysis of video-recordings suggests that video elicitation may be an appropriate method to explore what makes an effective patient-provider interaction. Questions used in the video elicitation interview process are presented in Table 6. Questions for Video Elicitation Interviews. This table reflects the template used for the elicitation interview guide with eight participating resident primary care physicians.

Table 6.      Questions for Video Elicitation Interviews

| Question Goal | Sample Question |
|---|---|
| Identification of patient-centered care strategies | As we review your visit with your patient, please be aware of any elements of care that you might perceive as being "patient-centered" in nature.<br>When you notice "patient-centered care" being performed, please pause the video and/or ask me to pause the video. |
| Thoughts, beliefs, and emotions | What were you doing/trying to do at this point in the visit?<br>What makes this moment in particular stand out to you?<br>How did you want the other person to perceive you? |
| Impressions of others | What did you think the patient was thinking about you at this point?<br>What were your impressions of the patient's actions at this point?<br>Why do you think the patient made that statement at this moment? |
| Impressions of self | What do you notice about your actions at this point?<br>What about your behavior at this point surprises you? |
| Decision making processes | What let you know that was the right decision to make at this point?<br>What information did you use in making this decision?<br>What other courses of action were you considering or were available to you?<br>What made you decide this was the right decision at this point in time?<br>How much time pressure did you feel in making this decision? |
| Barriers and Facilitators<br>*Addressed at commencement of the recorded interaction or when the resident asks to stop*s. | How pleased are you with the outcome(s) of that visit?<br>Do you feel you reached your goals for that visit? What about the patient's goals<br>Did you have the resources to meet your patient's needs?<br>How supported do you feel in delivering patient-centered care?<br>Is meeting the goals of the patient a priority in your practice?<br>What elements of your practice support your ability to provide patient-centered care?<br>What changes would you make to your practice in order to be more patient-centered? |

Note. Adapted From Henry & Fetters (2012).

The interview guide used in this study is presented in Appendix D: Video Elicitation Interview Guide.

In this portion of the study, eight of the fifteen (53.3%) consented residents participated in video elicitation interviews. Scheduling constraints and other pressures related to clinical and administrative activities prevented many of the residents from scheduling elicitation interviews within a feasible time frame concerning this element of the dissertation research. Results and interpretation of the eight interviews are included here. The remaining seven residents continued to express interest in participating in video-elicitation interviews and this element of the research agenda will continue outside of the context of this dissertation.

All interview discussions with residents during the video elicitation were audio recorded and transcribed verbatim by a neutral third-party transcription service. All transcripts were entered into QSR International's NVivo 9 software for analysis (QSR International Pty Ltd., 2011).

Thematic analysis was used to assess this collection of data. Themes were generated from resident responses and situated within the following broad topic areas related to the elicitation interview: thoughts, beliefs, and emotions; impressions of others; impressions of self; decision making processes; and barriers and facilitators to patient-centered care delivery. Results are presented in Chapter 4.

## Analytical Framework and Synthesis of Data

*In what ways do patient-provider interactions reflect the political and organizational goals of patient-centered care within Patient Centered Medical Homes?*

Patient-centered care is framed in this discussion as an outgrowth of macro-social trends, including the increased prevalence of chronic disease, organized efforts to implement multiple care delivery models, and payment reform efforts centered on quality and outcomes. Overlaying these trends is a conceptual understanding grounded in a socio-ecological model of health and well-being that emphasizes the role and impact of social determinants on health among individuals across populations.

Traditionally, biomedical realism and social constructivism have each offered an incomplete and often unsatisfactory account of how patient-centered communication research may inform inquiry into patient-centeredness (Parsons, 1975). Understanding that patient-centered care continues to lack an overarching integrative theoretical foundation, my data preparation and analysis intends to put the dualism of health care communication/interaction research on firmer ground by using an integrative social analysis approach. For example organizational inertia, resource constraints, professional dominance, team dynamics, and conflicting interpretation of definitions, value, and meaning have all been cited as barriers to effective implementation of patient-centered care (Daly et al., 2009; T. L. Fisher, Burnet, Huang, Chin, & Cagney, 2007; Légaré, Ratté, Gravel, & Graham, 2008).

I interpret the data generated by this research using a critical analysis of patient-centered care consistent with an Integrative Theory of Social Analysis as presented in Figure 2. Integrative Model of Social Analysis (Ritzer, 1990). The following concepts and associated data were utilized to construct this integrative discourse within patient-centered care activity systems:

1. *Macro-objective*: Federal policies, professional society guidelines, payment reform initiatives, incentives and state level efforts around patient-centered care. Informed by literature, policies, guidelines, and reforms.

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2. *Macro-subjective*:  Practice-level barriers and facilitators, norms, culture. Informed by elicitation interviews with provider participation.

3. *Micro-objective*: Observable elements of patient-centered care informed by GMIAS coding and CASE threading of dyad interactions between patients and providers.

4. *Micro-subjective*: Provider-level insight into patient-centered elements of dyad interactions with patients.

Approaching the research questions from a perceptive of critical inquiry, a perspective more closely tied to interdisciplinary social constructs of medical care, operates on a premise that introduces contradictions to basic assumptions of the traditional biomedical model. Utilizing Ritzer's approach in my analysis engendered a discussion that addresses many influences from a variety of domains as suggested by the proposed Ecological Model of Functional Patient-Centered Care presented in Chapter 1of this dissertation as Figure 1. Ecological Model of Functional Patient-Centered Care. This approach may have implicit theoretical and practical implications for future research regarding optimizing policies, environments, practices, and behaviors related to promoting the delivery of patient-centered care. A critical discursive methodology for analysis was employed in this research to work through the integration the primary research data with the macro elements of influence presented in the review of literature. Critical discourse analysis in this context serves to help un-package tensions and contradictions between and within discourses and the means by which discourse makes a particular statement or framing of an issue seems rational even though it may be only valid at a particular time and place, or within a giving set of activities (Chouliaraki & Fairclough, 1999). In this analytical framework, I look at interactions between family medicine residents and

diabetic patients as a particular discourse practice that health care providers produce, and for which they have acquired, or have acculturated, the rules of production. I analyze what discourses residents draw upon when interacting with diabetic patients, looking specifically at how patient-centered care is manifested. In this way, the residents' communication with diabetic patients, and the reciprocal talk, sets the conditions for the production of patient-centered care within the primary care setting.

The theoretical framework within which the critical discourse analysis takes place is cultural historical activity theory as presented in conceptual framework section of Chapter 2. Cultural historical activity theory views human activity as object-oriented, mediated by tools and discourse, and social and historical in nature. The main challenge in this research consisted of bridging activity theory and the method of critical discourse. This approach was both unifying and problematizing. It helped me to interrogate the different goals and objects within a defined (patient-centered communication) activity and explain why disturbances and or poor outcomes occur (Roth & Lee, 2007). This can help to develop a richer, more integrated and explanatory picture of patient-centered care activities and how they are sustained through the interactions and relationships between people, their actions and interactions within teams, organizations, and systems.

Furthermore, I do not establish that this type of analytical framework is the answer to all complicated research challenges. However, to increase understanding of how and why the processes and practices related to patient-centered communication and care are displayed and are sustained in a natural setting, the multidimensional and integrative method at the heart of this analysis provides a useful explanatory tool and

more inquiry using this approach, or variations of it, could help to refine methodology in a manner more conducive to actionable, participatory research.

## Issues of Trustworthiness

The trustworthiness of qualitative research generally is often questioned by researchers operating within a positivist frame; perhaps because these concepts of validity and reliability cannot be addressed in the same way in qualitative work. This is perhaps especially true when considering research that is grounded in between constructivist and critical influence like the research I conduct here.

As described in the researcher perspective section in Chapter 2 of this dissertation, the credibility I bring as a researcher to this endeavor is warranted through prolonged engagement in both the research setting as well as the familiarity with culture and organizational norms (Lincoln, Lynham, & Guba, 2011; Lincoln, 1992). As a health services researcher in the department of family medicine in which this study takes place, I am embedded in the structural norms of the environment. Additionally, regarding the video-elicitation methodology described earlier in this chapter, the process of participant review of interactions serves as a method of member-checking my assumptions and analysis. Member-checking has been described in numerous qualitative methodology texts as the most crucial technique for establish credibility (Creswell & Miller, 2000).

This research was conducted through a lens of critical theory grounded in epistemological and ontological tradition of social inquiry. I utilized a critical discourse method of analysis and I am fully aware that my methodological orientation affected the nature of this inquiry including choices and assumptions I made about the

characteristics and qualities of the communication behaviors and processes being studied.

## Limitations

This approach to investigating patient-provider interactions has several limitations. One limitation is that this analysis is not longitudinal. Physician-patient relationships develop and evolve over time. Another limitation is that the GMIAS, as a new method to characterize physician-patient communication, is descriptive in nature. While I do speculate that some of the patterns observed may not be ideal, I do not assert that there is any particular distribution of topic codes or pattern of speech acts that I know to be desirable or optimal, especially related to causation or prediction to health outcomes. An additional criticism of this type research, which holds true here as well, is that the sample of respondents is not statistically representative. Findings generated from this research may not be generalizable to a more diverse and larger-in-scope population of patients. Nor may the findings be generalizable to more specialized areas of care provision outside of the primary care setting, or related to care delivered by non-resident physicians. Additionally, the findings of this research may or may not inform practice behaviors among providers who treat patients with other chronic conditions within specialized health care delivery settings.

I want to also note that the labor intensity, time, and skills required for working with video and audio content posed tensions and challenges for the use of audiovisual documentation in real-world field research. Analysis of outpatient primary care visits coded with salient clinical and conversational topics can provide valuable insights into patient-provider communication, but it is a tedious and costly exercise. The intensity of audiovisual analysis and conversational interaction analysis were only tolerable

within the time-pressures and project-orientation pressures given its assumptions about turn-around time for research, analysis and reporting for this dissertation. These pressures include organizational and practice level constrains regarding the relatively new and exploratory methods carried out in this research as well as recognition that patient-care demands, practice performance and administrative responsibilities often take precedence over research within clinical operations.

This research into primary care interactions sought to improve understanding of patient-centeredness in primary care interactions by designing the study to focus on the kinds of data deemed meaningful and unrestricted by the most threatening bias to the study design. For example, regarding the video elicitation interview method chosen for second-level interpretive data, several limitations have been identified by social scientists (Calderhead, 1981; Gass & Mackey, 2013; Lyle, 2003). There are noted limitations in distinguishing whether comments during video elicitation interviews represent recollection, reliving, or reflection (Crandall, Klein, & Hoffman, 2006). By extension, participants' comments during an interview do not always reflect thoughts, beliefs, or emotions during that interaction. Participants in this study may have reconstructed thoughts, beliefs, or emotions based on the video recording rather than on their actual recollection or experience (Gass & Mackey, 2013). Admittedly, the multi-level approach to analysis chosen for this research is complex and time-consuming regarding use in routine professional monitoring, real-time review and feedback or critical clinical application such as accreditation and certification. There were lessons learned in this regard which can be applied to future research utilizing similar methodology and resources. The value derived from this type of exploratory analysis may help in creating more reliable, less complex methods in the future.

An additional limitation lies in the fact that the all data were coded and analyzed by an individual researcher, the author of this dissertation. This presents a limitation in the form of a singular research perspective in design, methodology, data collection, coding, and analysis toward a substantive validity. I have described my own philosophical groundings and assumptions in approaching the research questions presented here and I have been explicit that my research is designed to produce findings that are valuable towards pragmatic applications of policy, discourse, programs and didactic advancement within the realm of patient-centered health care delivery in primary care.

Given that this research is generally exploratory in nature and I have no personal stake in specific findings, the single-coder/investigator bias can be limited. However, there are institutional goals related to care delivery, payment reform, and other considerable implications of this research that may play a role in informing the methodological and theoretical decisions I have made. I am subject to influence of these institutional goals to the extent that they drive many aspects of organizational policy for my employer. To this degree, I am attentive to transparency in publishing details about methodology, interview processes and instructions to participants so that readers can better assess quality, reliability and potential bias.

Because of its grounding in this web of intra- and interpersonal relationships, the elicitation methodology proposed here provides important and qualitatively different information from many other more established sources, such as direct observation. However, while it is often rich and engaging, caution is applied here in concluding that it might represent a more accurate view of reality than the data gained from these other methods; it simply provides a different perspective.

## Chapter 4

## PRESENTATION OF FINDINGS

Findings from the analysis of coded speech acts related to patient-centered communication in fifteen interactions between family medicine residents and diabetic patients are presented in this section. First, results are shared regarding distribution and content of patient-centered speech acts at the utterance unit of analysis, followed by the distribution and content of these speech acts coded within threads containing patient-centered care process. Next, I present primary findings from eight video-elicitation interviews conducted with family medicine residents, reflecting on their interactions with diabetic patients.

### Learning From Micro-Analysis of Patient-Provider Interactions

The first selection of data presented here are drawn from a body of fifteen (15) audio recorded and videotaped adult, primary-care encounters between diabetic patients and family medicine residents collected from two, community-based northern Delaware family medicine practices between January 1, 2014 and March 15, 2014. Participants included purposeful convenience sample of fifteen (15) family medicine resident physicians and sixteen (16) of their diabetic patients. One resident physician was recorded twice interacting with two different patients, in which case, these data were averaged to the mean and used as one (resident) visit for the purpose of this analysis.

All data collection was approved by both the hospital system's institutional review board (IRB) and human-subjects' protection committee as well as the University's IRB. All physician and patient participants provided written informed consent to be recorded prior to the study. Additionally, both parties of the dyad were aware of the recording process at the time of the visit and provided permission to publish any non-identifiable information obtained from the recordings.

Of the sixteen patients, the mean age was 48.4 years (Range: 25 – 68 years), 62.5% were female, 31.25% of patients were White, 60.0% African American, and 6.2% Hispanic.

Of the fifteen family medicine residents who participated, the mean age was 30.13 years (Range: 25 – 42), 53.7% were female and 62.5% of residents were White.

Office visit length was a mean duration of 32:27 min and ranged between 15:41 – 49:53 min. Given the nature of the family medicine residency program, first year (PGY1) and second year (PGY2) residents are scheduled for forty to sixty minute visits with patients as a means to enhance clinical skills training. Therefore, visit length in this subset of visits was considerably longer than general primary care office visits which generally last about 15 minutes in duration (Tai-Seale, McGuire, & Zhang, 2007).

The median count of total coded utterances per visit was 489, ranging from 117 to 1147. The number of coded threads per transcript ranged from 5 to 39 with a median number of coded threads of 15 and mean 15.9. Sixty-three percent of threads were doctor owned but there was considerable variation among visits, ranging from 19.8% to 91.1%.

Table 7. Distribution of Patient-Centered Care Measures and Visit Length shows the distribution of the variables classified as measures of patient-centered care for this study among fifteen interactions between family medicine residents and diabetic patients.

Table 7.        Distribution of Patient-Centered Care Measures and Visit Length

| Variable | Definition | Range | Median (25th, 75th) |
|---|---|---|---|
| *Patient centered care variables* | | | |
| Percent patient expressive | Percent of total utterances (physician plus patient) that are patient utterances *and* have the expressive speech act code | 3.1 - 14.8 | 5.86 (4.2, 7.3) |
| Percent psychosocial content | Percent of total utterances (physician plus patient) that have the psychosocial topic code | 6.3 - 78 | 4.27 (12.3, 37.4) |
| Ratio of patient to physician utterances | Total patient utterances divided by total physician utterances | 0.27 - 0.66 | 0.48 (0.36, 0.52) |
| Ratio of patient to physician questions | Ratio of total patient questions to total physician questions | 0.4 - 4.8 | 1.22 (0.81, 2.7) |
| Percent patient "control" utterances | Percent of total patient utterances that have the control speech act code | 3 - 27 | 7.9 (5.2, 13) |
| *Visit length* | | | |
| Clock time | mm:ss | 15:41 - 49:53 | 32.27 (10:31, 21:41) |
| Utterance count | Total coded utterances | 117 - 1147 | 489 (159, 635) |

Context related to the information displayed in Table 7 is important in sifting through the data. Brief case descriptions of some of the patient-provider interactions

now follow as a means to contextualize the coded data. Much of the discourse initiated by residents in the interactions was concerned with the provision of information. Generally, the information related to some aspect of the diabetes, or other co-morbidity related to the medical condition of the patient. This discourse includes items such as the symptoms, the condition, the treatment, test results, or even the medical/hospital system itself. Such information was usually expressed clearly without the use of complex medical terms. Residents in the study rarely used medical jargon unless they were in the company of another doctor. Contextual detail from a particular encounter, Interaction 6, follows.

During Interaction 6, the diabetic patient initiated a large amount of discussion about issues which were coded as logistics, such as not appreciating the way she was treated on the phone when trying to obtain some pharmacy related information, the patient hints at wanting to transfer her primary care to a local clinic where her sister receives care. There was also considerable biomedical content coded to this visit, mostly initiated by the patient, which is not of great concern to the resident. This visit featured a great deal of interaction that was coded as socializing.

An important theme in most of the recorded interactions concerned the resident offering practical advice to manage a condition, particularly the patient's diabetes. This theme predominantly involved biomedical discourse but also included talk about aspects of patients' social lives and the domain of the health care system itself. This type of discourse included advice like health behavior preventative measures, suggestions for cost-savings related to diabetes testing supplies and referral to the diabetes educator that works within the office setting.

Some residents discussed broad social and familial issues with their patients in the management of their diabetes as well as taking practical everyday issues into account. Such practical advice included telling patients to place reminders or "sticky notes" for themselves in obvious sites concerning appointments and medication adherence, as well as talk about various hobbies patients enjoy with friends. Contextual detail from another encounter, Interaction 13, follows.

During Interaction 13, resident dialogue continued with a patient no longer characterizing her lifestyle changes as substantial enough related to the goals set at the previous appointment. Instead, the patient noted she has made many changes (as reported to the diabetes educator last month) but ends on an ambivalent note: "So I'm not being as drastic as before, but maybe I need to make a few more changes". The resident utilized the self-management notion of slow, sustainable change to argue that the patient's increasing awareness of what the patient was eating is an important first step, and reminded the patient that the drastic changes she has made in the past will not be helpful now. The patient challenged the resident's expectation. Here, the patient's reframing was inadequate to the resident, whose skeptical tone only ended after the patient listed future changes she hoped to make (exercise more, control portion sizes). Specifics regarding these changes were neither offered nor solicited during the interaction.

Figure 9. Distribution of Type of Speech Acts Owned by Residents and Patients shows the distribution of types of speech acts owned by residents and patients during the primary care interaction. Classification of speech act codes are presented on the y axis with distribution of ownership by patient of resident represented on the x axis.
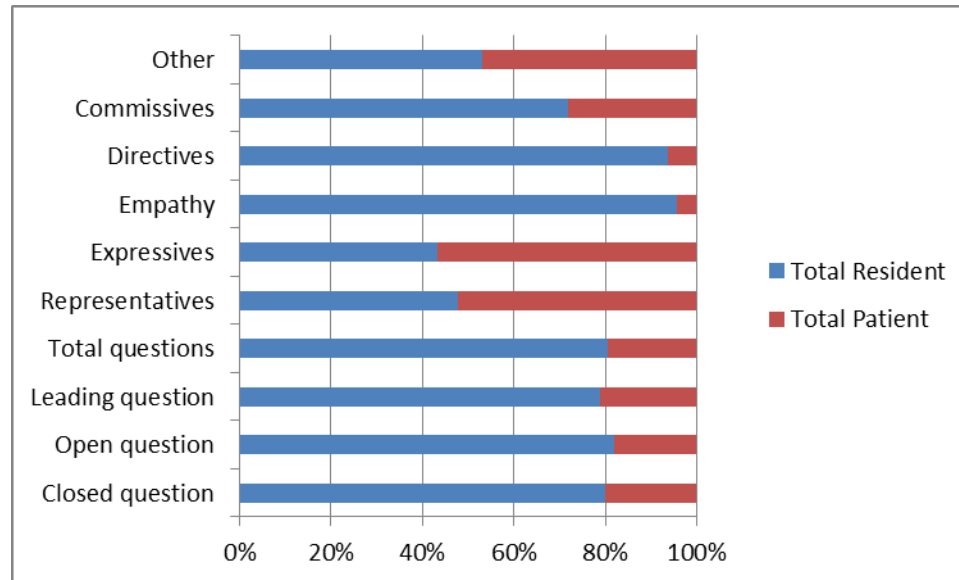
Figure 9.    Distribution of Type of Speech Acts Owned by Residents & Patients

Table 8. Distribution of Patient-Centered Speech Acts within Processes per Interaction, shows the mean number and percentage of selected speech acts within processes per primary care visit. These are patient-centered speech acts coded within patient-centered processes. Processes, including combinations of different processes, make up threads (see detailed description in the methods section of Chapter 3). Mean number of processes and percentage of total processes in each category are displays and assigned to an owner, either the resident (Res) or patient (Pat).

Table 8.    Distribution of Patient-Centered Speech Acts within Processes per Interaction

| N=15 | Presentation | | Information | | Resolution | | Engagement | |
|---|---|---|---|---|---|---|---|---|
| **Owner** | Res | Pat | Res | Pat | Res | Pat | Res | Pat |
| **Closed question** | 37.6 21.6% | 7.3 4.3% | 0.9 2.1% | 1.6 10.3% | 3.5 6% | 2.1 8.1% | 0.6 8.6% | 0.1 1.2% |
| **Open question** | 6.8 4.5% | 1.2 0.7% | 0 0.2% | 0.2 2.3% | 0.5 0.9% | 0.3 1.4% | 0.4 2.8% | 0 0% |
| **Leading question** | 14.9 8.2% | 3.4 1.9% | 0.3 0.7% | 0.8 5.2% | 1.8 2.7% | 0.7 2.4% | 0.5 5.7% | 0.1 1.2% |
| **Representatives** | 53 28.3% | 91.4 56.9% | 24.1 71.3% | 2.9 13.1% | 17.3 33.2% | 4.6 17% | 1.2 9.7% | 1.1 20.9% |
| **Expressives** | 9.4 5% | 17.5 9.8% | 2 5.8% | 0.8 2.6% | 3.2 4.8% | 2.8 8.4% | 2 23.8% | 1.4 22.4% |
| **Empathy** | 0.7 0.4% | 0 0% | 0.1 0.9% | 0 0% | 0.3 0.4% | 0 0% | 1.3 15% | 0 0.4% |
| **Directives** | 7.4 4.1% | 1.1 0.6% | 2.9 8.6% | 0 0.1% | 12.1 30% | 0.4 1.7% | 1.1 11.5% | 0.2 2.9% |
| **Commissives** | 2.5 1.6% | 0.9 0.5% | 0.1 0.2% | 0.1 0.9% | 2.8 9.7% | 1.6 12.4% | 0.2 0.8% | 0 1.7% |
| **Other** | 30.4 17.1% | 45.4 27.6% | 4.4 12.6% | 5.6 34.3% | 8.9 19% | 11.2 49% | 2.8 29% | 2.8 44% |
| **Totals** | 177.6 | 164.5 | 34.9 | 16.3 | 47.4 | 22.9 | 9.6 | 6.3 |
| Res/Pt % of utterances in process | 52% | 48% | 68% | 32% | 67% | 33% | 60% | 40% |
| % of all utterances In threads | 66% | | 10% | | 13.5% | | 3% | |

Presentation was the predominant process within this collection of interactions between family medicine residents and diabetic patients. The presentation process comprises 61% of all utterances and 65.8% of utterances within threads. Here, presentation processes yield a high proportion (24.2%) of provider utterances which are generally questions, and exemplify a strong flow of information from patient to provider (56.9% vs. 28.3% representatives). Of the total of fifty-six provider questions

per visit, forty-one (73.2%) were in the presentation processes. These findings support a well observed phenomenon of providers asking many more questions than patients in typical primary care visits. These questions are accounted for almost entirely by the presentation process in these visits.

As observed in the fifteen recorded primary care interaction between family medicine residents and diabetics, patients ask more questions than do residents related to the information process (mean 1.8 vs. 1.3) and the flow of information predominantly moves from provider to patient (71.3% vs. 13.1% representatives). At least one resolution process occurs in each visit. These constitute a smaller share of utterances, 13.5%, than do presentation processes but slightly more than information processes, 10%. Resolution processes in these cases were distinguished for the high proportion of provider directives (30%) of all provider speech acts coded in the visits.

Figure 10. Distribution of Type of Speech Acts Within Process & Ownership represents the distribution of patient-centered speech acts (color-coded) within processes assigned to residents (R) or patients (P) during primary care interactions between family medicine residents and diabetic patients. Processes and process ownership is presented along the y axis. Distribution of color-coded speech acts is represented on the x-axis in Figure 10.
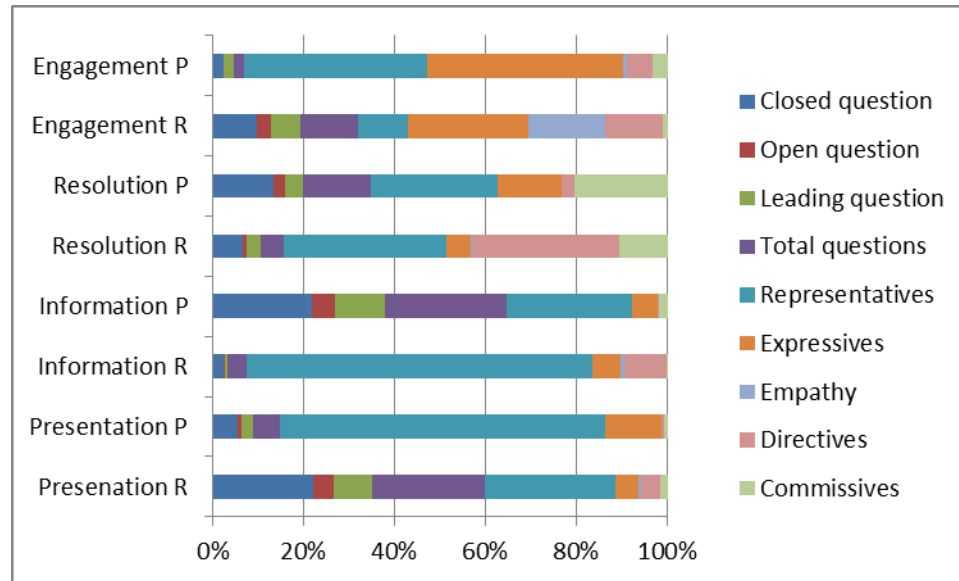
Figure 10.    Distribution of Type of Speech Acts Within Process & Ownership

Notably, engagement processes occur in each visit but they constitute relatively few utterances where they do occur. Intuitively, the engagement processes included a relatively high proportion of expressive utterances by both residents and patients. They also included a relatively high proportion of provider empathic utterances. However, it is notable that no other process includes even one percent of provider empathic utterances. When considering this case, it should be noted that the total average number of empathic utterances observed in this selection of primary care visits, where any engagement process occurs at all, is only slightly more than one.

## Deriving Context from Video-Elicitation Interviews

The first presentation of findings from the video-elicitation interviews is the relationship between the coded elements of patient-centered communication derived

through interaction-analysis of audiovisual date for sixteen primary care interactions between residents and diabetic patients, and the elicited identification of patient-centered elements of care derived from video-elicitation interviews with eight participating family medicine residents.

Agreement between patient-centered processes observed and coded by the researcher, and resident-identified elements of patient-centered care observed by residents through video-elicitation review was calculated using Cohen's kappa statistic. Cohen's kappa measures the agreement between two observers who each classify $N$ items into $C$ mutually exclusive categories. In this case, one observer is the researcher as coder of recorded interactions, and the second observer is the participating resident observing the recorded interaction of themselves with a diabetic patient. The video elicitation interview guide prompts the resident to identify elements of the interaction that are "patient-centered in nature" during the review (See guide, Table 6. Questions for Video Elicitation Interviews or Appendix D: Video-Elicitation Interview Guide). The reported kappa statistic 0.210 and is considered to be "fair" agreement. Parameters are presented below.

> Number of observed agreements: 121 (60.5% of the observations)
> Number of agreements expected by chance: 100.0 (50.0% of the observations)
> Kappa= 0.210
> Standard Error of kappa = 0.069
> 95% confidence interval: From 0.075 to 0.345
> Strength of agreement is considered to be 'fair'.

The result of this "agreement" measure regarding the Kappa statistic between myself and the resident physicians is less representative of standardized recognition regarding practical application of patient-centered communication technique, and more of a "member-check" regarding conceptual understanding of meaningful,

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humane connections being made between provider and patient within a care process. This distinction is not only relevant

The second presentation of findings in this section is generated from the primary qualitative analysis of eight video-elicitation interviews conducted with eight family medicine resident physicians. Three participants were male and five participants were female. Analysis was inductive, focusing on the interviews as whole entities. Interview data were transcribed into Word files and uploaded into NVivo 9. Interview data were analyzed using a multi-step coding process. Interviews were initially coded on deductive codes extracted from the theoretical and practical application of patient-centered care concepts, as well as barriers and facilitators to patient centered care at the structural and individual levels drawn from previous literature presented in Chapter 2. Deductive codes included clinical experience, stress, time constraints, concordance, therapeutic alliance, positive and negative experiences, interactions with patients, interactions with staff, among others. Inductive codes, however, professional identity, perceptions of patient-centered care, professional roles, patient-centered care ideals, among others, were identified through multiple readings of interview transcripts and the initial deducting analysis procedures described above. These deductive and inductive codes were then utilized in tandem to identify frequently appearing themes nested within the data. This coding process yielded several general themes and these themes were then employed as codes and all interview data were analyzed extensively to continually extract processes behind themes. Four major themes emerged from the analysis described in the following segments of this section. These themes can be classified as responsibility, relationship, complexity, and advocacy.

The second step entailed identifying the meaning units that referred directly to the act of delivering patient-centered communication or providing patient-centered care. Next the meaning units were compared so as to find agreements and variations and were further grouped into themes. The themes were further organized into a set of categories related to the question goals of the elicitation interviews (See Table 6. Questions for Video Elicitation Interviews or Appendix D: Video-Elicitation Interview Guide). For example, regarding the theme of responsibility, deductive and inductive codes such as professional roles, interactions with patients, self-identity and self-reflection, and other-orientation were found to frequently converge, often relating to the notion of providers' increased sense of wanting/enjoying/desiring to care for others. This general theme was then utilized as a code and the entirety of the data was analyzed again to further specify the intricacies of the theme and how residents were truly discussing the issue. Each of the themes is discussed in the section that follows.

Family medicine residents recognized the ways their behavior influences subsequent patient behavior. This theme is closely related to residents expressing a desire to elicit further disclosure of pertinent information that can help them take better care of their patients.

> I have to assess what I have to do differently to establish a good
> rapport, and um and so I – my introduction to the patient may be
> slightly different. (PGY3)

> My facial expressions, my response to his comments, you know . . .
> should I be smiling or laughing at times to encourage him to tell me
> things I need to know about his health? (PGY2)

Residents recognized the value of learning to pay attention to the subtleties of patient behavior. This theme is closely tied to resident desire in gaining a fuller picture of their patient's life. Statements made by participants indicate that this was directly in line with supporting their patients' ability to manage their diabetes.

> The patient has a name, a life, a family and a history. You have to look at the bigger picture now. (PGY1)

> …sitting down and having my eyes at her level or below her was so important there… I know I am, but I want patients to know I'm gonna be honest with them if they're honest with me. (PGY4)

Residents interest in reflecting on their own growth and awareness as trusted care providers. A significant concept identified by residents within this theme is that of responsibility. This theme is connected to residents' reflection about communication and some of the structural elements of patient-centered care delivery classified as facilitator or barrier.

> One of the things I love is learning from patients. They have have great stories, man. Sometimes it's heartbreaking, but I feel like I have a responsibility to listening to their stories. They teach me… it sort of leads my plan of action. (PGY2)

> It's essential that I get exposed to my patient's story, that you're actually incorporating it as part of your practice from the beginning… of the relationship. (PGY3)

> In terms of challenges, volume is a big issue. We want to spend enough time with each individual patient so we can actually make a difference, because if we're not doing that we're completely wasting our time. But that's not really conducive to managing a financially sustainable practice right now. (PGY4)

Residents identified significant personal and structural barriers related to their ability to deliver patient-centered care at the level they felt was "up to par". Some residents pointed out that they have dual roles. Residents posit one role is to address patients' basic social needs, the other to address medical needs. Comments provided by residents within this theme seem to relate closely with empathy, a core element of patient-centered care and communication and was a mostly tied to recognition that they have a responsibility to serve as advocates for their patients.

> Sometimes, I feel really bad saying 'I don't know' to patients because it seems they expect more of me than they did even a year ago. Now that I am the doctor, they see me as the expert. (PGY1)

> We have to try to make this office and the hospital even, a place they want to come to, not an extra responsibility or a burden. We have to minimize the disruption we impose on people's lives. (PGY3)

> There's probably too much of, 'you need to focus on just learning the clinical stuff.' We need to know about how life works for our patients. When we can do that, we can start to fit ourselves, as physicians, into the larger picture of what is going… that is creating this environment. (PGY4)

> I think there has to be an innate-ness, or cultivation from your early years, you can't be a good communicator from… if you're not able to communicate well by the time you become a doctor I don't know whether you're ever going to be a good communicator. (PGY3)

However, here again the position is partly ambivalent and tinged with paradox, because if the relationship with the patient is the attraction, it can also be perceived as a burden. Residents acknowledged the complexity of their patients, not just from a chronic disease management standpoint, but also how this "management" impacts patients' lives.

What is the burden of treatment we put on patients when we push them and push them to try and get their BP [Blood Pressure] down, to try and get their A1c down? We just keep doing all these things to get their markers better, but they don't always like that. That's hard - that's a lot of medicine… a lot of prescriptions and lots of visits and a lot of pokes checks, and a lot of really difficult behavior changes. (PGY3)

Many of our patients have pretty serious problems. Like, mental health illness has to be a critical element to complex care. If you don't have the opportunity to integrate primary and mental health, you won't get good outcomes. (PGY4)

It takes a village to do this kind of care well. I'm not sure we have the types of resources or the incentives to make sure we can all link. We need the community people [community health] on board, and they need us but it's just not happening as best as it could. (PGY3)

Technological tools, most notably the presence and use of the electronic health record, were discussed by residents in terms of both facilitator and barrier to delivering patient-centered care.

It's nice to see that I don't look rushed in the exam room. Although in my mind I'm busy and probably a bit disorganized. Okay, so I sit down, I try to relax and look relaxed and I think when I turn away from the computer, I get much more of his [patient's] attention (PGY2)

This [video] is interesting to watch, because I'm… I'm even though she's talking I'm not looking at her, I'm… I'm semi-listening to her. This is really good feedback for me because I should probably kind of …probably like looking at her face more . . . she knows that I'm paying attention, I'm nodding and everything. I'm okay with that, but I should probably look at her more. (PGY1)

Generally speaking residents do not feel there is an inherent crisis in primary care in general and family medicine in particular. Some feel guilty, or at least uneasy

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and torn between a sense of responsibility to meet a societal need that is generally

upstream from hospital practice, and fulfill family medicine's vision of itself, and a

sense that it is impossible to do it all, to incarnate the entirety of "family medicine

foundations" in their individual practices. In responding to this tension, residents

identified a value in a team-oriented approach to patient-centered care. Some of these

elements have been implemented in the practice, such as health coaches and diabetes

educators.

> I think for me, as a physician, I always thought I was supposed to do everything and that I was supposed to be the best at doing everything. And then working with other people… I realize others can teach patients better than I can. And they'll try to do it in a way that patients really appreciate, maybe even more than when I try to. (PGY4)

> Everyone on the team has a skill and some of those skills I don't have, and I can let them do that piece of it and not try to do it myself. Sometimes it's a real weight lifted. But I still feel accountable to the patient so I have to trust the other providers. (PGY3)

Comments by some residents focused on reflection of their medical judgments

in relation to awareness of the situation being more pronounced during the video

review.

> There's usually some concern that [the patient is] sometimes beating around the bush… they won't come out and tell you that . . . you have [to] dig at it, especially if you can feel if there's something that wants to come out. (PGY3)

> When you have a patient that comes in and everything is wrong with her, so that to me is a red flag to like start looking for evidence of depression or to maybe start in on the psychosocial stuff. (PGY4)

Another important theme that emerged from the interviews was the apparent gulf between residents, younger physicians for that matter, who embrace the added dimensions of the profession and the more seasoned physicians, both inside and outside of the family medicine specialty, who exhibit a more traditional approach to patient care. This element of discourse was tied to both the responsibility and advocacy themes. For example, residents felt that most among their more experienced colleagues, while being able advocates for patients, are perhaps less concerned with barriers to addressing the social determinants of health.

> Once you come out of your residency training, I really think you are woefully undereducated in thinking holistically about patient care and under-resourced in being able to deal with it even if you wanted to. (PGY4)

> If I have some doubts with the visit, that I could have done better, I always discuss it with (senior physician), I say, "What can I have done better? What would you have done?" I'm looking for that type of advice and it's always helpful from a clinical view, but I still don't feel like it's enough. (PGY2).

> If I could do one thing to improve [diabetic patient]'s health? I'd like to find him steady employment. (PGY4)

Four major themes of responsibility, relationship, complexity, and advocacy emerged from the video-elicitation interviews with family medicine residents. Elements of the video-elicitation interviews that informed these themes provide a foundation for critical discourse in analyzing the micro and macro components of patient-centered communication as a means to move patient-centered care along the orientation of health reform goals.

**Summary**

The goal of this chapter was to inform the reader of the micro-analytical findings derived from the primary research conducted for this dissertation. Primary research results were presented here in two parts, the first included data from a micro-analysis of sixteen audio-visual accounts of primary care interactions between diabetic patients and family medicine resident physicians in two practice settings. These findings reflect the nature and distribution of patient-centered communication elements as they occur during the interaction between diabetic patients and their health care providers in a primary care setting.

The second selection of findings presented in this chapter included data from eight semi-structured video-elicitation interviews with family medicine residents which utilized audiovisual recordings of their participation in interactions with diabetic patients as a means to elicit context, meaning, barriers, and facilitators regarding the delivery of patient-centered care.

In Chapter 5, I interpret these data first in each part, then in an integrative manner using an approach informed by critical discourse analysis within cultural historical activity theory.

# Chapter 5

## ANALYSIS AND INTERPRETATION OF FINDINGS

*"The greatest mistake in the treatment of diseases is that there are physicians*
*for the body and physicians for the soul, although the two cannot be separated."*

-- Plato, (427–347 BC)

In Chapter 5, I analyze and interpret the findings presented in Chapter 4. First, I describe how the information resulting from the exploratory micro-analysis of sixteen primary care interactions between family medicine residents and diabetic patients clarifies how the content, ownership and distribution of communication acts during the primary care encounter may support or hinder elements of patient-centered care in the office. Next, I interpret the findings from eight family medicine resident video-elicitation interviews and describe how this information can provide context to micro-analysis, revealing contradictions and tensions between therapeutic intent, goals and activities in the delivery of patient-centered care. I conclude the chapter by interpreting these data in an integrative critical discourse analysis to assess patient-centered care using findings from the primary research conducted for this dissertation, along with relevant literature from a variety of disciplines such as medicine, social sciences, health care management, philosophy and ethics, health policy, and organizational studies.

Three primary findings emerged from the exploratory research conducted within the context of this dissertation. First, examination of the micro-level process related to patient-centered care in primary care interactions between family medicine

residents and diabetic patients shows that patient-centered care patterns across visits tend to follow a generally common pattern of speech acts, processes, and socialization features. Here, more research is needed to begin to distinguish preferable patterns related to practice-level and system-level goals for patient-centered care related. Although the findings of this micro-analysis are somewhat expected given the system-level influences, pressures, and incentives placed on particular care delivery models, it also establishes a baseline from which to engage a critical analysis aimed at uncovering prime areas for reform and innovation.

Second, analysis of the primary research data derived from the video-elicitation methodology provides a meaningful mechanism for better understanding the context and meaning given to certain speech acts, socialization features, and activities during primary care visits between diabetics and residents. Participating family medicine residents were able to identify and clarify patient-centered care processes that were more tacit in nature and were less evident to me as an observer/coder. Further, residents who participated in this exercise were able to identify specific elements of patient-centered care that were in fair agreement with coded observations across a variety of interactions. This indicates that residents are aware and knowledgeable about when and how to apply patient-centered communication techniques in the care of their patients. This point may underscore the importance of critical, reflective analysis in identifying structural and/or systemic barriers to the provision of meaningful patient-centered care.

Third, the critical discourse method used to synthesize the range of findings generated in this research is a particularly useful tool for employing critical reflection of system-level goals, actors, activities, and knowledge generation related to patient-

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centered care. I employed this approach to generate a collection of archetypical patient-centered care ideals which could be utilized as recognized "base-lines" when taking a critical approach to innovation in practice re-design, strategic planning at the system level, and policy implementation.

## Understanding Patient-Provider Interactions

Examination of the micro-level process related to patient-centered care in primary care interactions between family medicine residents and diabetic patients shows that patient-centered care patterns across visits tend to follow a generally common pattern of speech acts, processes, and socialization features. This was somewhat expected, as similar patterns are found in other health care communication literature using comparable interaction analysis coding schemes yielding similar results. The fifteen recorded and coded primary care visits between family medicine residents and diabetic patients were dominated by the presentation process. The presentation process is defined as the development of information about the patient's specific condition, symptoms, experiences or history. The resident reports about test results or clinical outcomes. In this collection of primary care visits, this process made up 61% of all utterances, 66% of all utterances coded to threads. Given the nature of this exploratory research, I cannot comment about whether this result is too much, too little, or just right in relation to the optimal delivery of patient-centered care. However, assuming that visit length in primary care is often limited and or constrained by structural practice demands, any more information exchange, shared decision making, or patient-centered engagement would have to come at the expense of presentation processes. Given the variance of utterance and process distribution within this

selection of recorded visits, I cannot assume that all of the factors that might influence the delivery of patient-centered care are accounted for in this micro-analysis of interaction between family medicine residents and diabetic patients.

The results point to a second observation regarding patterns of speech acts in the aggregate across an entire primary care visit. This type of aggregation can be misleading in relation to any observation that information flow during the presentation process, often seen across visits in a pattern of questions and representatives, is from patient to doctor and the information process flows mostly from doctor to patient.

It can be thought that it is in the patient's best interest for the physician to be asking most of the questions and for the patient to be providing most of the information. This sort of dialog and interactional arrangement meets the practical need of both parties to achieve a shared understanding of the different problems under discussion. This could be assigned to a patient-centered approach termed shared decision making, reviewed thoroughly in Chapter 2 of this dissertation and elsewhere (Frosch et al., 2012; Makoul & Clayman, 2006a). Likewise, during the information process, it is arguably in the diabetic patient's interest to be asking the majority of question and hopefully eliciting empathic response from the resident. The appropriateness of these patterns can only be appreciated if patient-centered processes are coded and separated as they are in this analysis.

Another important finding generated from the micro-analysis of patient-provider interaction in primary care is that speech and utterance patterns in the resolution process are distinct from other processes in ways that may have implications for shared decision making. This relationship is also evident in the coded resolution processes when compared to other processes. Generally, a high proportion

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of directives may be a function of the time pressures that residents feel in relation to practice management pressures. This may be revealed as a sense that a directive approach is more effective than decision making that is more shared, or both. Additional research is needed that examines whether a less directive method of interaction produces better engagement, better clinical outcomes, or more patient activation towards chronic disease management.

An additional important observation is the apparent scarcity of interaction elements related to the engagement process. While there is unquestionably a great deal of instrumental process that needs to happen in any visit, I was surprised that overall, less than three percent of all utterances were classified in the engagement category. It may very well be that providing emphatic reassurance and emotional support are not needed in some interactions, or are only necessary in limited quantities in routine visits for patients with chronic conditions like diabetes. Here, empathy is a complex notion that needs to be further discussed and unpackaged.

The literature suggests that more and better interpersonal and emphatic chronic care in general, is associated with better medication adherence, better patient-engagement and greater patient satisfaction (Beach, Roter, Wang, Duggan, & Cooper, 2006; Thornton, Powe, Roter, & Cooper, 2011b). Debates surrounding what is meant by empathy can merge to form a case study for developing discursive thinking about communication beyond the current, dominant reductive models of instrumental skills or competencies. This is one of the core reasons for critically exploring interaction analysis with multi-methods as done in this dissertation. Therefore, I do not make a case *for* empathy, but suggest the potential for further critical studies of empathy as an illustration of the departure of serious thinking about communication in professional

relationships, primarily in the context of patient-centered care delivery in an era of health care reform.

This does not implicate any intervention or educational opportunities aimed at, perhaps, improving the nature of the questioning that goes on during the presentation process in the office visit. For example with more open ended questions and more inquiry into patient experience, understanding of values and perceptions, the presentation process, as defined and used in this dissertation research, could be improved (Heritage & Maynard, 2006; Heritage & Maynard, 2011; Robinson, 2001). Additionally the information process could potentially be improved or tailored to more patient-centered approaches, with the use of reflective techniques such as teach-back and the video-elicitation method explored in this research (Chou & Lee, 2002; Sudore et al., 2009).

While this analysis has emphasized the structural orientation of interactions between family medicine residents and diabetic patients in primary care, it is important to stress that this results not in an argument against the use of standardized trainings of patient-centered communication skills specifically, or communication skills more generally. I believe that this caveat is essential here because describing internal contradictions or mixed messages in a social logic is often seen as an attempt to invalidate or undermine this logic. I am not necessarily making that case. It may be, for example, that primary care practice, and the medical profession in general, is intrinsically pulled between the technical and the human sides of its practices, such that attention in training to patient-centered communication skills may be carving a precarious path between conflicting values. It may also be that such dichotomies are deeply ingrained in modern formations of actors and subjects in relation to their goals

within an activity system, such that one could not fairly expect the health care practitioners to dismiss such fundamental concepts that are more generally rooted.

I will apply caution to my analysis here for a few reasons. This was my first attempt at using this coding system on a very dense and robust arrangement of audiovisual data and refinement of my technique may be justified. Additionally, given the nature of this exploratory analysis, I make no judgment as to the external validity of the findings related to this approach. To the extent that the primary research conducted here on a small sample of sixteen primary care interactions is reliable externally, it is recognized that critical structural elements of practice design, outcome goals, incentives, and training that took place within the family medicine practice environment studied in this dissertation are comparable to the meso and macro-level influences in place among large, legacy health care institutions throughout the country. This concept is explored in more depth later in this chapter.

**Understanding Resident Elicitation of Patient-Centered Care Perceptions**

It is important to note that for all resident physicians who participated in the video-elicitation interview process, the main aim of the individual patient encounter, including all actions and collaborations with or for an individual patient, was aimed at the practice good medical care. I do not doubt or seek to be critical of actions or intent related to any activities observed or reported on here, but rather aim to utilize findings from this element of the primary research as mechanism for contextual clarity. This element of the exploratory research performed in this dissertation is designed to enrich my understanding of the multitude of factors and meanings related to patient-

centeredness in primary care from the perspective of the family medicine resident as a primary actor within an activity system.

Qualitative analysis of the eight video-elicitation interviews helped to clarify some of the findings from the micro-analysis of primary care interactions. For example, diabetic well-visits were unusually long in some cases because of the inherent biomedical and psychosocial complexity of managing chronic disease among a selection of patients with very complicated lives. Residents who participated in the elicitation exercise noted that while this notion was often true, in most cases visits were longer because of attention to specific patient-oriented agendas. This is a prime tenant of patient-centered care and as such, was acknowledged immediately by participating residents as the primary driver of most of their encounters with patients.

The discussions that unfold during the breadth of the primary care interactions were often noticeably different in each set of circumstances and reflected both the unique approaches to care delivery expressed by the residents, as well as the residents' acknowledgement of needing to attend to each patient as an individual. Patient-driven agendas often feature more complex narrative and a great deal of expressive and emotional content. To the contrary, physician-driven biomedical agendas are characterized more by representative speech acts over the course of the visit. Elliot Mishler highlighted this difference in dominant "voice" of the clinical interaction by contrasting *The Voice of Medicine* and *The Voice of the Lifeworld* (Mishler, 1986; Mishler, 1984). Mishler described physicians thwarting patients' efforts to tell their stories in their own narrative voice, and constraining the conversation within a biomedical frame. In the long, patient-driven visits, the residents do not do this, and the voice of the life-world emerges.

This concept has important implications in this research because during the video-elicitation process, residents were generally able to recognize the distinction. This showed in residents' ability to notice a potential contradiction between their intent during a particular segment of interaction, and what was actually playing out on the screen in front of them. This was most evident relating to inherent conflict between attending to the tools and techniques of biomedical chronic disease management and residents' concern for patients' psychosocial, behavioral, and structural determinants. It was also revealed in residents' concern and conversation regarding patients' ability to self-manage their diabetes.

By supporting patients to self-manage, residents believed that they were providing a holistic approach to health care. They sought to ensure advice was targeted to the individual patient and addressed, as appropriate, physical, nutritional, social, and emotional aspects of their lives. For example, as part of providing patient-centered care, some residents who were interviewed identified consideration for other influences on their patient's health. Some of the most frequent considerations reported by residents included co-morbidities; the patient's home situation and contextual markers related to the management of chronic disease.

However, these findings begin to illustrate how primary care interaction that is heavily focused on self-management can bring tension to the clinical relationship beyond highlighting patient-oriented behaviors deemed challenging. Here, dialog between patient and provider regarding self-management of health risks may run the risk of over-assigning patient responsibility for clinically oriented outcomes. Research in the area of self-management suggests that this may lead to patients feeling less

motivated for acting on and maintaining sustainable changes (Blakeman, Chew-Graham, Reeves, Rogers, & Bower, 2011).

In some of the interactions, behavior change was stressed primarily as a means to achieve defined clinical endpoints that are biomedically relevant to chronic disease management. When this occurs, the possibility that a patient would be positioned as a failure entered the dialogue (Lorig, Ritter, Villa, & Armas, 2009; Piette, Heisler, Horne, & Caleb Alexander, 2006). This type of relational positioning during the primary care interaction may elicit some cautious interaction from patients who were perhaps guarding themselves against excessive or unrealistic goal setting within the context of the social and structural influences on their ability to self-manage (Nam et al., 2011). That is, patients resisted over-estimations of their individual ability to control biomedical outcomes via behavior change. This positioning underscored the potential for failure, so to speak, and it derailed self-efficacy oriented conversation which required visit time to address and even attempt to mitigate.

Residents often discussed information, sometimes as non-verbal behaviors that they deliberately employed for patients in order to influence or steer communication or leading questions. This often had to do with the quality and/or the comfort of the relationship. Several residents adjusted their posture, gaze or speech to improve connection with the patient for communication. Residents' comments suggest that during video-elicitation interviews they did recognize these behavioral elements as influencing their ability to construct an effective clinical relationship. Residents also discussed how judgments they made based on patients' body language and non-verbal behavior affected their medical decision making and the trajectory of the interaction. These types of judgments were mostly related to mentions of patients' emotional well-

being, feelings or attitudes, rather than decisions about medical management or decisions about specific chronic disease management techniques. The residents' accounts of planning, decision making, treating, and support in individual patient processes showed, however, that patient-centered support of patients, were enacted, even though not explicitly articulated. For example, deliberate strategies displayed by the residents and highlighted in Chapter 4, included provision of patient-centered learning and support, but these were both varied and somewhat limited.

At its most basic, discourse analysis requires understanding that individual attempts at self-expression are fashioned from existing, shared communicative resources that are learned socially. Patients and family medicine residents assumed new roles for goal of effective chronic disease management. These goals may have conflicted given the "voice" in which it originated. Family medicine residents who participated in this research generally understood their role as expert care provider, but made explicit that the reassignment and integration of various roles is a common element of primary care practice when framing patient-centered solutions. This was revealed in the kinds of tensions observed and expressed in the analysis of both micro-level and more macro-level influences.

Mitigating the rising prevalence of chronic disease and crushing economic costs associated with managing it is a core directive of modern health care policies and this is reflected in practice arrangements, choice of care management techniques and tools, and selection of care team members. It has been argued throughout this dissertation that the biomedical acute-care model is ill-suited to the needs of patients with chronic illnesses, and thus requires a re-alignment of health care services, facilitated by new, effective interventions focused at meeting the patient's needs both

bio-medically and psychosocially. Specifically, modern medicine, reflecting the enormous postwar investment in biomedical research, was seen as neglecting the whole person of the patient, who was a psychological and social being as well as a biological one. Family medicine residents in this study reflected the stance that the biopsychosocial model of health care delivery and the patient-centered care model are complementary. From the residents' point of view, the former was proposed as an ethically neutral model of evidence based medical science while the latter puts science in an ethical context and is largely driven by the ability to relate.

The next section of Chapter 5 represents an integration of the micro-level findings resulting from the primary research conducted for this dissertation with the macro level components and influences of patient-centered care presented in the cultural-historical review of the literature in this dissertation.

## Towards Theoretical and Practical Integration

The primary research data presented in Chapter 4 and analyzed in the two previous sections of this chapter begin to make clear in practice, the tensions, contradictions, and disincentives that exist within the current orientations toward delivery of patient-centered care. To the extent that these findings are generalizable in similar settings, it is important to understand that the political and organizational goals that serve to shape the activity systems in which interactions are studied for dissertation, are also serving to shape care delivery systems throughout the nation, and beyond.

First, I return to the political and organizational goals of current health care reform efforts relative to the Triple AIM of better health care experience for patients,

better health outcomes across populations, and lower per capita health care costs (see Chapter 1, Introduction and Appendix E: Definitions of Terminology). The breadth and consistency of the health system underperformance across chronic disease categories suggests that the health outcomes in the United States pay a penalty for extreme fragmentation, financial incentives that favor procedures over comprehensive longitudinal care, and absence of organizational strategy at the individual system level (Moses et al., 2013).

Moses and colleagues describe three major forces that will change health and medicine in the decade to come. First is consolidation and industrialization, resulting in a much smaller number of much larger insurance companies, hospital systems and integrated systems consisting of both. This consolidation of the health care system in general, is resulting in fewer general hospitals and more single-specialty hospitals and physician groups, producing financial concentration in health systems, insurers, pharmacies, and health care benefits (Moses et al., 2013). The second major force of change being guided by reform efforts is information technology, in which investment has occurred but value is elusive. Health information technology is promising to coordinate care and improve quality but, despite large investments, has not yet delivered on the promise (Buntin et al., 2010; Finkelstein, Barr, Kothari, Nace, & Quinn, 2011). Third is the patient acting as an informed consumer, gaining greater influence in decision making within the care delivery setting (Moses et al., 2013).

These forces create tension among patient-centered aims reflected in the seminal texts in the conceptualization of patient-centered care presented in Chapters 1 and 2. Tensions and disincentives emerge in the patient-centered values such as choice, personal care and disease management plans, and emotional support and

attention to psycho-social needs. Following the logic of Figure 1. Ecological Model of Patient-Centered Care presented in Chapter 1, I draw the connection between the structural changes occurring across the health system and how these shortfalls are represented at the level of individual interactions between residents and patients. In the micro-analysis of patient-provider interactions, a relatively standard pattern of communication activities, turn-taking, and socialization occurred across the sixteen interactions observed, coded, and analyzed. The primary research findings presented in Chapter 4 reflect process, structure, organization, and ownership of communication acts between family medicine residents and primary care diabetic patients that addressed the technical and administrative needs of the office visit quite well, but it was notable that the patient-centered care attribute of empathy was nearly missing across encounters. This is to be expected if we place a primacy on the power of organizational and structural influences on care management in the clinical setting.

As stated earlier in this chapter, however, this notion of emphatic care for individual diabetic patients was extremely evident in the video-elicitation strategy used to establish context for these interactions. Residents were very adamant about feeling like they have a responsibility to advocate for their patients, and a driving force behind that advocacy was reflected in residents' concern for upstream, social determinants of the health of their patients. In problematizing empathy, it necessarily demands complexity and ambiguity in an era where the infrastructure of medical activity is being shaped by reform efforts that are primarily concerned with simplification, clarity, instrumentalism, empiricism, and measurement. The tension present here is manifested in the fact that there is no mechanism built into the activity system of the family medicine resident's care delivery system that incentivizes

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addressing these needs in a practical and results-oriented manner that is compatible with the administrative and system-level concerns of the practice.

Furthermore, tensions are present related to health care provider aims for professionalism and autonomy and public and private payer cost-control aims for aggregate economic value across large populations (Rittenhouse, Thom, & Schmittdiel, 2010). Measurements of cost and outcome related to population health (applied to populations and the distribution within groups) are supplanting individual preferences. For example, at the encounter level, individual patient empowerment is likely to be incompatible with a prescriptive decision aids geared to cutting costs. In this case, primary care providers are increasingly expected to substitute social and economic goals for the needs of a single patient. This tension was reflected in the primary research data gathered for this study. Primarily, most of the participating residents expressed being in favor of their patients' involvement in care plans and decisions regarding management of diabetes during the recorded interactions. This principal of shared decision making is a core element of patient-centered care discussed in the review of literature. However, many of the residents also expressed their position that their ability to make critical disease management prescriptions during the visit was of more immediate primacy than involving patients in the care plan. Here, these tensions were mitigated slightly by the introduction of other care-team members such as diabetes educators. Additionally, these discussions, when coded in the micro-analysis of interactions, consisted mainly of questions and directives generated by the resident with an implicit goal of obtaining information from the patient that might advance the technical component of the primary care interaction.

These contradictory forces are difficult to reconcile, creating a risk of growing instability and tensions as more structural changes, such as standardized accreditation of patient centered medical homes within large, consolidated accountable care organizations, advances the priorities related to political and organizational goals of health care delivery. The conflict among patient desires, physician interests, and social and health care policy is certain to increase. One focus area that the primary research presented in this dissertation helps to elucidate is that the younger generation of health care providers, family medicine residents in particular, express a concern in addressing these tensions both at the micro level as well as the macro level. As such, they might prove highly receptive to different incentives, bring refreshed subjectivity and objectivity, and embrace broader, more diverse social and political measures of success, such as those that reflect the value of their clinical judgment and their ability to advocate for their patients beyond the walls of the clinical setting.

Understanding and addressing the tensions presented here in a critical manner could become the main sources of innovation in patient centered care. Similarly, altogether new entrants may enter the arena and would fully mobilize people, information, and technology in ways not currently envisioned. Tensions will likely become a palpable force that drives various attempts at integration and inhibit other changes that favor improved outcome and cost savings. The usual approach to mitigating these tensions has been to address each constituency in isolation rather than optimizing or trying to understand how to integrate efforts across them. In the following section, I use a critical discursive approach to interpret how these tensions and disincentives can be used to understand goals, ideals, and innovations around patient-centered care delivery.

**From Contradiction and Disincentive to Innovation and Ideal**

Patient-centered care concept and measurement instruments in family medicine mainly refer to the approach and behavior of family physicians during the care process. Measures of patient-centered care have always been relevant to family medicine at a clinical level to reflect the concordance of practice with one of its core values. It is becoming increasingly important, however, as an organizing principle for change in health services delivery at a systems level. Themes such as human variability, subjective experience, and clinical intuition are all better addressed through the application of inquiry grounded in the concept that meaning is central to human knowing and those actions and behaviors are not wholly separable from the motivations and thoughts of the people who perform them. The last decade has witnessed broad and sustained efforts in exploring the multilevel, multidimensional nature of patient-centered care (D. J. Cohen et al., 2008; R. M. Epstein, Fiscella, Lesser, & Stange, 2010b; Scott et al., 2008; Stange, 2012; Stange, 2009b). Core to primary care are the view of the whole patient, the ability to deal with the uncertainties of people's illnesses, and the evolving context-dependent dynamics of both health and illness over time. Beneficial outcomes are achievable for populations strongly linked to a favorable level of primary care implementation, with a primary focus on individually appropriate, patient-centered and equitable care. As such, primary care functions in adaptive cycles of growth, accumulation, restructuring, and renewal within an ever-changing health system.

Based on the results of this multi-method study, it seems very relevant to discuss patient-centered care as an interconnected set of activities. To be patient-

centered is to see the patient as an individual. It is to try to understand what the illness means for the particular patient and to understand the broader social and psychological context that influences factors of health and well-being. Family medicine residents in this study listened to their patients' point of view to try to understand their needs and values and to attempt to share responsibility with them. But it is not just one of these things. Each of these components is a fiber running through the thread of patient-centered care, giving strength to the whole and becoming a reinforcing mechanism for dealing with psychosocial determinants of health.

Despite the positivist episteme and praxis orientation of the traditional health care model, when dealing with the issue of patient-centered care the coexistence of two different dimensions can hardly be disregarded. Health improvement derived from patient-centered care can be understood both in terms of biological control of process, intent and outcomes, as well as experiential knowledge, concordance, and partnership.

The question is, however, whether the meaning of health, illness, suffering and well-being are taken for granted and as such, prematurely prioritizes operational and organizational concerns, and the economic emphasis of this meaning. In addition there may also be a prioritization of a political view of being human that emphasizes rights and empowerment. The essence of my critique here focuses on the question of what both the economic and political emphases leave out of the equation when bearing in mind the essences of health, patient-centered care and overall quality of life. Additionally, I present a broader critique of the current neo-liberal arrangements of health care as it is currently practiced, including the reductionism, epistemological restrictiveness, materialism, and general neglect not only of the whole patient-as-person but also of the whole clinician-as-person. The results shown in this research

leave much doubt that the current economic and political emphasis fully encompasses the kinds of concerns and knowledge that are adequate for approaching the breadth and depth of patient-centered care relevant to us as human beings – whether a patient, or a provider.

First, the "whole patient versus their parts" is a clear tension present in the results of this research, as well as the literature explored in Chapter 2. Among physicians who do not specialize, like the family medicine residents participating in this research, the whole patient—the biopsychosocial one–is the most suitable focus of care delivery. In general, patients may be treated as wholes rather than parts only in the context of primary care. As described previously in the work of Barbara Starfield, one of the four defining characteristics of primary care as currently understood is "long-term person- (not disease) focused care" (Starfield, 1998).

To the extent that generalist primary care providers like family medicine doctors practice biopsychosocial care, this model of patient-centered care is advanced by policies and organizational arrangements to support them. However, none of these policies has been successful in increasing the proportion of primary care physicians. For example, adjustments to physician payment infrastructure under the Resource-Based Relative Value Scale (RBRVS), medical school loan repayment programs, and a number of provisions under the Accountable Care Act are characteristic of this type of effort (Gillam & Maudsley, 2010; Jolly, 2005). The ACA provides financial incentives to primary care physicians in the form of higher reimbursement under fee-for-service Medicaid (expanded in many states under the ACA) and a longer term pay bonus under Medicare (threatened by current political opposition) (McCormack & Burge, 1994; The American Medical Association, 2009; J. White, 2013).

The patient versus provider tension is evident in the results of this research as well. The version, or archetype, of patient-centered care arose from the health care consumer movement that began in the 1970s (Binkley & Capetillo, 2009; Kaplan, Greenfield, & Ware, 1989; Stevens, 2006). The consumer movement sought to increase patients' control over the medical services they received, both in the consulting room and in the health care market. The fact that Americans are "hailed" as consumers of health care matters because the labels we use to describe the beneficiaries of the health care system shape the assumptions we have about how that system can and should work (Lakoff & Johnson, 2008). Other voices of health care consumerism adopted the language of the capitalist market. They proposed that health care professionals be subject to the same market discipline as commercial vendors. This was an exercise of economic rather than political power except for when the regulatory state might be summoned to protect consumers (J. S. Hacker, 1997). In this formulation, patients have the right not only to be heard by their health care providers but to choose freely within a "marketplace" and control decisions regarding their options for care. Furthermore, under the economic theory of moral hazard, consumers bearing more of the cost of their care would create a more efficient market and thereby lower overall costs (J. Hacker, 2009). This is reflected in the current marketplace arrangement of health insurance products facilitated by the Affordable Care Act. Additionally, many of the insurance plans being touted as affordable within the health insurance marketplace maintain a lower monthly premium payment by shifting more cost-sharing to patients in the form of more expensive co-insurance, co-payments and deductibles at the time of service delivery (Benjamin, Slagle, & Jones, 2013; Ooms, Derderian, & Melody, 2006).

Explored in the results of this research at both the micro and macro levels, shared decision-making identifies its roots in the health care consumer movement that includes a patient challenge to physician authority (Charles, Gafni, & Whelan, 1999; Frosch, Legare, Fishbein, & Elwyn, 2009). It is distinguished from other models of medical practice like the informed decision-making model, whose physicians merely purvey information, and the professional-as-agent model whose physicians decide what the patient would have wanted had he or she been equally as informed.

On the one hand, a citizen versus consumer model that overly emphasizes personal or collective self-management and self-authority is partial because it underemphasizes patients as exposed and vulnerable, regardless of their social status. On the other hand there have been reductionist versions of a 'medical model' that overemphasize illness and underemphasize the phenomenon of human agency. When people become patients they want to be seen in both their agency and vulnerability and feel unmet by interactions that emphasize one or the other. One element of what I have been able to show in this research is that family medicine residents desire to be catalysts for activating a more ideal model of patient-centered care. This is an important function to consider when applying a critical, integrative method to understanding patient-centered care activities within highly structured practice and health care system settings.

As I indicated above, the issue of patient-centeredness has been dominated by its dichotomous origin in the literature. Patient-centered medicine is generally positioned as a response to the proliferation of evidence based medicine (Bensing, 2000), which itself was positioned in response to issues relating to fragmentation of effective care, health inequalities, and disparities in health outcomes (Lasser,

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Himmelstein, & Woolhandler, 2006). Current performance measures throughout primary care evaluate adherence to guidelines and best practices, irrespective of the patient's individual circumstances and behaviors or the context. As of yet, there has not been an organized, systematic process for assessing whether such evidence based practices are applied judiciously to the care of individual patients or across needs-relevant aspects of sub-groups of patients . As these measures regard fragmentation specifically, there are a number of recent policy developments aimed at reducing this threat to patient-centered care and the "medical home", discussed at length in Chapter 2, is a primary example.

Current health policy discourse frequently references the perverse incentives operating in the US health care system. These are incentives, economic, legal, and professional, that motivate providers to act in their own interests and not those of patients (Bob Roehr, 2012; G. A. Cohen, 1992; Timbie, Fox, Van Busum, & Schneider, 2012). Fee-for-service reimbursement and malpractice liability represent two such incentives, both of which are seen to contribute to unnecessary and potentially harmful care. In this arena, tensions are also visible in nature of the health care system itself. Most healthcare organizations operate in a complex context of conflicting demands and objectives, multi-faceted and often highly challenging daily tasks, a demanding environment teeming with a highly diverse body of professional clinical staff (Nembhard, Alexander, Hoff, & Ramanujam, 2009; Ramanujam & Rousseau, 2006). Therefore, as patients' progress along the care pathway, the delivery of effective health care very much depends on the careful collaboration and inter-change of information among various individuals, organizations, occupational groups, multidisciplinary teams, and allied health services.

Structural changes in the social organization of health care have facilitated convergence between doctors and patients by constraining the construction of personal role identities within patient-provider dyads. Changes such as the mobilization of informatics, big data, disease registry and growing management of the health of groups and populations have re-framed structural impulses for population level care and associated performance management for economic and disease markers (Buchanan, 2008; Naumova & Cohen, 2008; Phillips Jr., Dodoo, & Green, 2005). This has necessarily framed and consolidated clinical encounters into pseudo-corporate services across organizational interfaces. Health care providers and patients are each expected to squeeze their interests in personal health care into larger, health policy boxes for population health care. However, as physicians and other care providers adopt the potentially contradictory roles of patient advocate and societal steward of scarce health care resources, patients begin to understand their need to help protect their own role identity and interests (Buetow, Jutel, & Hoare, 2009; Campbell, Roland, & Buetow, 2000).

Elements of these tensions were shown in the results of this research presented in Chapter 4. Conversational micro-analysis of patient-provider interaction showed clear emphasis towards addressing chronic disease management in a structured question, process and information exchange format led by the physician with particular conversation and socialization rituals aimed at accomplishing clinical oriented goals. Consequently, residents participating in the video-elicitation interviews expressed an awareness and understanding of this tension regarding their ability to meet the needs of the patient within the context of time management, resource access, and other influential practice norms. Table 9. Patient-Centered Archetypes as Ideals

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represents a culmination of the critical discourse analysis and integrative, cultural

historical approach applied to the findings of the primary research conducted for this

dissertation as well as supporting literature across a variety of disciplines found

throughout Chapter 2.

Table 9.    Patient-Centered Archetypes as Ideals

| Patient-centered models & their missions | Nature & scope of orientation | Accommodations in practice | Supporting policies and mechanisms |
|---|---|---|---|
| **Whole patient vs. part of patient, e.g., disease, organ system** | Biopsychosocial model, positivist social science + medical science | Family medicine; primary care delivery; Integrated physical and mental health care | Equitable pay in primary care; residency slots for primary care |
| **Patients vs. providers: 1. Political 2. Technical** | 1. Individual knowledge and preference 2. Aggregate preference; decision analysis | Shared decision-making; Patient satisfaction surveys; Clinical decision aids | PCORI; value-based purchasing using satisfaction surveys |
| **Patients/providers/states versus the "system," i.e., perverse incentives** | Economics and engineering; clinical epidemiology | Care coordination, case management, patient navigators; Integrated delivery systems | PCMH, ACO; bundled payments; money follows patient |
| **Patients and providers as persons** | Narrative and interpretation; Multiple ways of knowing | Medical education; reorganization of care activities and goals | Macro-level cost controls; hospital accreditations |

In this arrangement, various models of patient-centered care are conceptualized

as solving problems in the US health care system. Advocates of each type contend that

centering on the patient will mend distinct failings in health care as it is currently

arranged at the interaction, organization and system level. The models here have epistemological orientations, practical accommodations, and are influenced by specific policy guidance and tools.

The ordering of models in Table 9 is roughly chronological, as established in the review of literature (see Table 2. Historical Perspective of Primary Care Practice Redesign), but does not necessarily signify a progression towards any better solution of patient-centered care orientation. The models are presented here as a relative "baseline" for critical discourse towards innovative care delivery models.

The first model, "Whole patient versus part of the patient" responds to the reductionism in scope of biomedicine and offers positivist social science approaches for use in primary care as a strategy for improvement. The second model, "Patients versus Providers", responds to the disempowerment of patients in a paternalistic relationship with providers and system incentives. This model approaches solutions via political and procedural forms. Health care consumer movements elevate patients' involvement in knowledge generation, resource allocation, and care delivery preferences; formalized shared decision-making and patient survey analysis moderate these elements but represent patients with new forms of independence, and objective autonomy. The third model, "Perverse incentives" responds to the economic, political and professional incentives that produce health care system which are not responsive to patient needs. Outcomes here are usually representative of under treatment as well as over treatment, care fragmentation, and system reorganization which prioritizes economic (capital) growth. The fourth model, "Patient and providers as persons" represents a relatively new and as yet developing model of patient-centered care with roots in humanist, phenomenological and narrative medicine. The elements derivative

of this model mainly consists of resources and goals that are unified towards a response to evidence-based medicine. The first model challenges a successful biomedical science, the second model is challenges a powerful organized medical profession, the third model reshapes a wealthy, consumption oriented health care market, and the fourth model portions resources to address all of these targets as well as opposing the objective dominance of evidence based medicine. In every case, a renewed focus on patients provides a counterweight to the goals and objectives of other actors, activity systems, and institutions.

In the Chapter 6 conclusion to this dissertation, the interpretation and analyses constructed in Chapter 5 will be used to unpack some of the ideal models of patient-centered care as models within which a critical discourse can be applied to address recommendations in the research, practice, and policies environments pertaining to patient-centered communication, patient-centered care, and health care policy in general.

## Chapter 6

## CONCLUSIONS AND RECOMMENDATIONS

### Conclusions

Problems in health care are problems in society. The health system, and the myriad of activities throughout, is so intimately tied to the broader society that attempts to study one without the other lead to insufficient conclusions and misleading rhetoric. These problems often emerge from social contradictions and cannot be separated from those contradictions (Waitzkin, 2000). The transformation of health systems in response to the social, demographic, and chronic disease, and resource constraints, are also shaping the fundamental elements of interactions between patients and providers, as well as the organizational structure in which they interact.

Among the most notable issues in health policy, organizational development and the redesign of clinical practice over the last fifty years have been those centered on changing dynamics in clinical encounters, predominantly in enhancing the relationship between physicians and their patients. This is also reflected in how patients access and utilize health care. Examining the evolving professional, social, and institutional dynamics affecting clinical encounters and help-seeking is informed by and benefits from sociological concepts, and can promote more effective health care practices and policies. The interest in the patient-provider relationship and its implications on the provision and outcomes of health services has brought about the emergence of more complex and interconnected models of care (Singer et al., 2011; Stille, Jerant, Bell, Meltzer, & Elmore, 2005). Since these issues encompass broad

areas of care-seeking, they are especially important in individual, institutional and policy goals for achieving high quality, effective patient-centered care. The medical specialty of family medicine is situated in precisely the optimal place to not only respond to these changes, but to be on the leading edge of integrating social responsibilities with population health goals.

Different models of patient-centered care presented in Chapters 4 and 5 were explored through a critical discursive account of the major research findings here, and in the varied literature base. The meanings, features and reflections of patient-centered care observed, analyzed, and reported in this dissertation culminate in the concept of patient-centered care affixing to each a mission to remediate health care. Some models challenge a successful biomedical science; others check a powerful medical profession; some archetypes operate against a wealthy health care market; and other models share all of these targets. In all cases, a transformed focus on patients provides a counterweight to the excesses of other policies, institutional influences, and actors.

These models all describe alternative forms of this relationship. Such ideal descriptions exemplify role changes in the doctor–patient relationship, including a progressive shift toward more modern, democratic and equal modes of participation in information exchange and decision-making. However, these descriptions cannot account for the social forces that have led to their changing and enterprising development. This requires a more dynamic set of concepts that can accommodate the effects of modernity on the role development of patients in their interactions with health care providers of all stripes.

Caution and thoughtful consideration is applied however, as the patient-physician relationship appears a particularly important, yet vulnerable asset in system

reforms. It is the element of care that most specifically addresses illness through a sustained therapeutic relationship and as such, it has the potential to be a motivator of upstream social advocacy related to fundamental changes in the determinants of health. In addition, given the complexity of models of health system reform, an expanded framework is needed to be able to engage the dichotomous nature of organized approaches to managing disease, health, and illness. In this research, I suggest that a strategic mechanism for this type of critical approach is recognition and understanding of the tensions, contradictions, and disincentives in an activity system, such as the delivery of patient-centered care within organized practice settings with institutional goals. I conclude that such an approach helps practitioners and administrators to focus their efforts on the root causes of problems. This type of collaborative analysis and modelling is a crucial precondition for the creation of a shared vision for any potentially expansive solutions that might emerge from these contradictions.

As medicine becomes less situated as a "profession" and more situated as a "business" in the United States and elsewhere, there is a need to revisit structural inquiry of the patient-provider relationship. While talk of individualized and personalized medicine is the relationship rhetoric being marketed within the new "patient as consumer" business model, it is not at all clear how these concepts will be implemented in a manner that respects matters of physician expertise, judgment, and advocacy as well as patient autonomy, authority, and agency. The conflicting nature of these relationships is particularly of interest when the goal is connecting long-term health outcomes along a socio-ecological spectrum. I surmise that this is of particular interest in establishing more valid and reliable benchmarks of population health.

Ultimately, the type of critical approach to inquiry used in this dissertation places many root causes of chronic disease, illness, and despair well outside of the traditional medical model (Mechanic, 2008). Legacy institutions like academic medical centers, large hospital systems, organized medical professionals, public health systems, and universities that do not adjust their orientation to attempt to address health and well-being from this perspective run the risk of becoming obsolete within a generation.

Keeping the patient at the center of care and striving to continually improve clinical practice should require the persistent collection of patient satisfaction and engagement data to enable iterative improvement of the integration of decision aids into patient care. What does it mean to be "patient centered" and what does this then mean about ways of improving health care systems, communication and dissemination, and generation of knowledge? Putting a primacy on understanding and improving the interaction between the patient and the provider may indeed be the only way in which the quality of health care delivery is ultimately improved; especially in a reform-oriented care delivery system which emphasizes and incentivizes patient-centeredness.

**Recommendations for Research**

This exploratory research attempted to draw together a conceptual and theoretical approach to understanding the mediators and effects of patient-centered care through integrated, multi-level discursive analysis. This approach shows that relationships between patients and health care providers cannot be described adequately by relying on the analysis of interactions between them. Researchers will need to integrate the micro-analysis of clinical and behavioral observations with

participant perspectives in order to understand what makes for authentically caring clinical relationships.

As described previously in this dissertation, lessons from this approach may have significant implications for teaching and practice, too. Health care provider interactions with patients will potentially be evaluated differently depending on whether the interaction is compared with currently influential and empirical views of patient-centered communication, described throughout the review of literature in this dissertation, or within a socially-oriented construction of health and illness. This research takes the micro and macro influences on patient-centered care provision and analyzes it as an activity within a cultural-historical framework.

A materialist approach to understanding patient-centered interaction using critical discourse analysis within a cultural historical framework has the potential to promote the development of innovative research questions in translational and health services research. It does so by changing the scope and orientation of these questions. Instead of asking, for example, whether a particular technology effectively promotes a certain health outcome, or the a particular effectiveness of one style of counseling in weight-loss interventions, a more structurally-sensitive research question would inquire about how asking such questions fits into the larger project of designing effective healthcare systems and what implications these changes might have on social determinants of health. Doing so would require at least some attention to the circulation of discourses both in and between various practitioners and patients as well as the variety of disciplines, both inside and outside the walls of the hospital, necessary for effective care delivery.

This approach to constructing relevant research questions in health care will necessarily treat the research context as a "self-contained totality" (Bhaskar, 1998). In this vein, some evolving research questions might be posed in this sort of research setting:

1. What are the ongoing empirical regularities within the context in question?

2. What are the most essential structural relations in this context?

3. What structural relations account for specific empirical regularities?

4. What historical events account for the rise of this or that set of relations?

5. How have these empirical regularities and structural relations changed over time?

6. What are the primary causal forces of this change?

I believe there is need for further and more sustained theoretical and conceptual synergy between health services researchers, medical sociologists and health policy analysts, and patients themselves, in order to provide on a cutting-edge and thought-provoking basis for the analysis of contemporary health reform on the one hand and on the other hand enables the development and elaboration of theory.

A growing body of health services, public health, and health policy literature advocates in favor of structural-level, integrative interventions to improve patient-centered care aimed at long-term improvement of health outcomes (Best et al., 2003; Bourgois, 1999; Salmon et al., 2011; Stange, 2009a; Verhoef, Mulkins, Kania, Findlay-Reece, & Mior, 2010). Researchers increasingly recognize that local policy

environments and other structural factors external to any empirical research designs like randomize controlled trials, may alter outcomes and obscure intervention effects. Statistically discrete variables may confound complex social processes, especially those laden with the complicated power dynamics and cultural ideologies found within patient-provider interactions (Binkley & Capetillo, 2009; Hobbs, 2009; Nicolaidis et al., 2010). The often contradictory effects of overlapping social influences and vectors do not have a causality-friendly linear effect on health outcomes, especially related to complex chronic disease management.

Researchers and teams of diverse and multidisciplinary researchers must situate themselves to collect precisely these kinds of complex "process data". This approach, ideally both translational and participatory in nature, can identify the systemic bias, contamination and other intervention effects that often confound epidemiologists, biostatisticians, and health care administrators (Hansen, Holmes, & Lindemann, 2013; Nathanson, 1996). Most importantly, when research focused on patient-centered communication and care models is guided by critical social science and subjectively formulated in historical and contemporary context, an integrative analysis can enhance explanatory power, help explain causality and recognize the logic for unforeseen outcomes (Messac, Ciccarone, Draine, & Bourgois, 2013). It can also propose new hypotheses and themes for ongoing participatory and critical discursive inquiry.

The role of this type of health services research, in my view, is exemplified in the coordination of the various discourses, approaches, and findings of other team members. The synthesis of these research efforts among a variety of disciplines could evolve into an artful arrangement, one that would implicate changes at every level of

health care from provider-patient dialogue to practitioner training, institutional design, and the deployment of a variety of health technologies to address the limits of the clinical environment. I believe this approach should be participatory and interdisciplinary in nature, and strive to enhance a more equitable and persuasive dissemination of research findings from one context into another.

## Recommendations for Practice

We have all sought or received treatment from health professionals at one time or another, and in that role most of us have felt some form of distance from the ideal healing relationship we would most want. Who among us, then, can easily resist the intuitive appeal of the phrase "patient-centered care"?

Clearly the myriad of definitions for patient-centered care presented in the review of literature, and throughout this dissertation, leave ample room for interpretation depending on the goals of specific patient-centered activities. Providers, practice managers, administrators, and health system leadership should reflect critically on the contradictory and dichotomous nature of this rhetoric. What does partnership mean in the context of health care interactions historically characterized by roles such as the expert clinician and the needy patient? What does it mean to participate in one's own care or to guide medical decisions - are these the same as having control?

Research shows when resident doctors received specific training based on models of self-directed learning, it resulted in satisfying individual development and improvements in practice performance. However, resident doctors described learning barriers ranging from competing demands in daily work and patient-centered care to

difficulties in goal-setting and care planning (Mukhopadhyay, Smith, & Cresswell, 2011; Thörne, Hult, Gäre, & Dahlgren, 2014). The interplay between physicians' own learning and their support of others' learning in daily work (i.e., pedagogical processes embedded in work) seems to be an almost unexplored field, even though learning is seen as necessary for health care providers' knowledge development and for the quality of healthcare in general.

However, if we reduce complex, aesthetic, and ethical everyday communications to instrumental, standardized competencies, there would be no need for understanding context and the structural and cultural influences that shape the very context deemed important by the actors of patient-centered care activities. If we frame communication as a problem to be solved and as a set of competencies to be performed or achieved, then we produce communication within the parameters of a definition and we produce conforming identities of actors who follow this pattern. At the core, this is the tension being observed throughout this research.

Furthermore, researchers recommend that the next phase of patient-centered medical home evolution should focus less on "supply-side" definitions where the emphasis is on infrastructure, personnel, Information Technology, and the organization of care delivery (Berenson et al., 2008b; Naumova & Cohen, 2008). Instead, the focus should be "demand-sided" where implementation takes into account what the consumer wants and meaningful differences across cohorts and sub-groups of patients (Jackson et al., 2013; Schwenk TL, 2014). To achieve this, it is important to seek participatory and engaged input from various stakeholders like patients and community organizations so that the care model can be tailored to the needs, preferences, vulnerabilities and expectations of patients.

One of the critical and under-appreciated attributes of primary care is its flexibility in adapting to different sociopolitical climates, populations, communities, individual patients and available clinicians and practice workers. The practice of medicine, chronic disease management, and organizing systems of care delivery, has changed radically through the past half-century. Electronic health records, merging of health care practices into corporate structures, hospital systems and accountable care organizations, all influence the patient-provider relationship and impact the philosophical and practical application of patient-centered care. The primary research conducted in this dissertation demonstrates why potential patients, current patients, physicians and teams of health care providers should be aware of possible ramifications of such influences. The integration of the primary research findings and the literature base suggests a critical discursive approach that focuses on tensions within systems of patient-centered care activity as a mechanism to better designing care delivery models as a means to innovate solutions to blatant and subtle contradictions.

Additionally, I showed that the video-elicitation method can be a useful tool not only for improving understanding of patient-centered care practices, but also for health care providers to critically reflect on actual practice and achieve better alignment with intent, goals, and outcomes. Further, this exploratory study suggests that this approach can lead to creative and innovative ways of re-thinking and re-designing patient-centered care to better address the socio-ecological needs of patients and communities and to better appropriate resources that aim to rectify social determinants of health and health equity.

## Recommendations for Policy

Policy leaders agree that a robust and organized system of primary care is at the center of a high-performance health system (Davis et al., 2011). As reform advocates seek to lower costs, increase access, and improve quality in the American system, organized family medicine, and the students, residents, and physicians throughout its ranks, will continue to be called on to lead change and advance patient-centered care models. The patient-centered medical home model is a promising avenue for reform that improves patient experiences of care, clinical outcomes, and physician satisfaction with medical practice, but as this research shows, careful critical consideration of the activities, communities, and goals of specific reforms is paramount. Leaders in research, practice and policy must continue to seek out and provide the financial and technical assistance necessary to initiate multi-level discourse and inquiry into models of patient-centered care. Inviting policy debate that involves social sciences, philosophy, and health services views points provides a forum of potentially innovative solutions that is richer than the sum of the parts.

Kingdon, whose multiple-streams theory is concerned with agenda setting, argues that the public policy process has a random character, with problems, policies, and politics flowing along in independent streams (Kingdon, 2011). In this theoretical orientation, policies might emerge from a problem stream containing both the broad problems and conditions facing societies, some of which become identified as issues to act upon via public attention. Under this conditional framework for policy change, consider superimposing a cultural-historical activity approach, similar to the conceptual framework used in the research for this dissertation. Engaging the advocacy potential of the politically potent elements of organized medicine, including groups like the American Academy of Family Physicians (AAFP), and the more

progressive Physicians for a National Health Program (PNHP) to organize activity around health equity and health disparities issues could potentially nudge the policy discourse towards upstream social determinants of health like poverty, housing, and economic inequality (Daaleman & Elder, 2007; Folsom Group, 2012; Himmelstein & Woolhandler, 1989). The purposes of such mobilization may depend upon the specific organized activity and can be seen as focusing events to set a more progressive, activist policy agenda for family medicine which centers on patient advocacy from a health equity and social determinants platform (Kingdon, 2011; Mu, Shroff, & Dharamsi, 2011).

Considering health policy in general, approaching critical issues using a theoretical and analytical orientation like the one employed in this research should initiate reflection pointing towards the structural, cultural, and historical activities that set policy agendas. The logic then leads to a set of questions that might look something like the following: Is the policy goal to mitigate the symptoms, of poverty or of ill-health, or to remedy the causes? Do we practice patient-centered care to reach some other goal, such as reduced cost, or is it a goal in itself? To what extent are policies and programs being funded and enacted for the benefits of certain advocates and champions? Where does the power originate from and where does it terminate? To what extent is the focus of health policy on individuals or "consumers"? Is the focus on their behaviors and attitudes, or on the community and its structural contribution to poverty and ill health? Are patients here individuals or part of the aggregate? How do we know what a patient wants and needs? Is the patient's expertise of experience considered legitimate? What about the health care providers? These are questions we must continue to ask ourselves if our true intent is to design systems of humane,

patient-centered care delivery. These questions are not necessarily meant to elicit approval or support of any specific model of patient-centered care but rather to highlight possible tensions and contradictions among the many elements of patient-centeredness explored throughout this research and elsewhere.

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# Appendix A

# INSTITUTIONAL REVIEW BOARD APPROVAL

**CHRISTIANA CARE**

Institutional Review Board
**FWA00006557**

Helen F. Graham Cancer Center & Research Institute
West Pavilion - Suite 2350
4701 Ogletown-Stanton Road
Newark, Delaware 19713

302-623-4983 phone
302-623-4989 phone
302-623-6863 fax

## MEMORANDUM

Steven Kushner, MD
Chairman, IRB #1
Gary Johnson, PhD
Chairman, IRB #2
Jerry Castellano, Pharm.D, CIP
Corporate Director
Janet Leary-Prowse, MSEd, CIP
IRB Education Specialist
Heidi Derr, BA, CIP
IRB Regulatory Affairs/Auditor
Sonia Martinez-Colon
Executive Assistant
Judy Hutt, BS
Administrative Assistant

**DATE:** September 30, 2013

**TO:** Brian M. Rahmer, PhD (cand)
Family Medicine Research
Christiana Hospital

**FROM:** Sonia Martinez-Colon

**RE:** *CCC# 33200* - **Patient-Provider Interaction in the Primary Care Environment: An Integrated Social Analysis of the Adoption and Delivery of Patient Centered Care.: (DDD# 602442)**

This is to officially inform you that your protocol was approved by Expedited Review per *45 CFR 46.110(F) (5) (6) (7)*, by Jerry Castellano, Pharm.D, CIP, Corporate Director of Christiana Care Health System Institutional Review Board, on **09/18/2013**. Approval was granted for a period of one year, from **09/18/2013** through **09/17/2014**.

The above stated CCC# (Christiana Care Corporation number) has been assigned to your research. That number, along with the title of your study, must be used in all communication with the IRB Office.

Changes in this protocol after the initial approval may not be initiated without Institutional Review Board review and approval, except where necessary to eliminate apparent immediate hazards to the human subject. Also, if you encounter any adverse effects or deaths that must be reported to the company and the FDA, the committee must be so informed immediately by phone.

In addition, a periodic review of this protocol will be conducted in six months to a year from the above approval date. At that time, you will be required to complete a review form with all available information collected to date on your protocol.

A final requirement is that you notify the Institutional Review Board when this protocol is completed, and all results are to be summarized for the committee's review.

If you have any questions, please contact the IRB Office.

*This approval verifies that the IRB operates in Accordance with applicable ICH, federal, local and institutional regulations, and with all GCP Guidelines that govern institutional IRB operation.*

DATE:                           October 23, 2013


TO:                             Brian Rahmer, PhD (Cand)
FROM:                           University of Delaware IRB

STUDY TITLE:                    [527005-1] Patient-Provider Interaction in the Primary Care Environment: An
                                Integrated Social Analysis of the Adoption and Delivery of Patient Centered
                                Care
IRB REFERENCE #:
SUBMISSION TYPE:                Other

ACTION:                         APPROVED
APPROVAL DATE:                  October 23, 2013
EXPIRATION DATE:                September 17, 2014
REVIEW TYPE:                    Administrative Review


Thank you for your submission of Other materials for this research study. The University of Delaware IRB
has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study
design wherein the risks have been minimized. All research must be conducted in accordance with this
approved submission.

This submission has received Administrative Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and
insurance of participant understanding followed by a signed consent form. Informed consent must
continue throughout the study via a dialogue between the researcher and research participant. Federal
regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to
initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the
appropriate adverse event forms for this procedure. All sponsor reporting requirements should also be
followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use
the appropriate renewal forms for this procedure.

# Appendix B

# IRB APPROVED CONSENT FACE SHEETS

**CHRISTIANA CARE**
HEALTH SYSTEM

## INFORMED CONSENT FOR RESIDENTS

**TITLE OF STUDY:** Patient-Provider Interaction in the Primary Care Environment

**PRINCIPAL INVESTIGATOR:** Brian M. Rahmer, PhD (Cand.)

**CONTACT PHONE NUMBER:** Brian M. Rahmer 302-320-6524

**SPONSOR:** Christiana Care Department of Family and Community Medicine

**INTRODUCTION**

You are being asked to participate in a research project that will involve observation of video and audio recordings of your interactions with patients. Your participation is voluntary. Your decision whether or not to participate will have no effect on your relationship with Christiana Care Health System, either clinically or educationally. Please ask questions if there is anything you do not understand.

The person responsible for this study at Christiana Care is: Brian M. Rahmer, Health Services Research Manager in the Department of Family and Community Medicine.

**WHY IS THIS STUDY BEING DONE?**

The purpose of this study is two-fold. First, the study aims to identify observable elements of patient-centered communication in the primary care setting. This study also aims to gain your personal feedback and insight into the delivery of patient-centered care within your practice. This might include barriers and facilitators as well as your own personal practice philosophy. Additionally, understanding how you and your patients communicate can help to improve how we how we train and educate resident physicians.

**HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?**

Fifteen (15) residents will take part in this study locally. All participants will be Family Medicine resident physicians at either the Wilmington Annex or Foulk Road location. Each of the 15 residents who participate in this study will be observed twice.

**WHAT IS INVOLVED IN THE STUDY?**

This research is intended to be an exploratory field trial. Resident physicians will be videotaped giving cancer screening and prevention advice to patients. To allow evaluation compared to a control group, the education intervention will be phased in. Initially, we will select a convenience sample of 15 residents (approximately half) to receive feedback.

CHRISTIANA CARE HEALTH SYSTEM
INSTITUTIONAL REVIEW BOARD
CCC#       33200                          Page 1 of 5
APPROVAL DATE:        09-18-2013                    Resident Initials:_____
APPROVAL PERIOD      09-18-2013                          Date:_____
        THROUGH      09-17-2014

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# CHRISTIANA CARE
## HEALTH SYSTEM

<u>**INFORMED CONSENT FOR PATIENTS**</u>

<u>**TITLE OF STUDY:**</u>  Patient-Provider Interaction in the Primary Care Environment

<u>**PRINCIPAL INVESTIGATOR:**</u>  Brian M. Rahmer, PhD (Cand.)

<u>**CONTACT PHONE NUMBER:**</u>  Brian M. Rahmer 302-320-6524

<u>**SPONSOR:**</u> Christiana Care Department of Family and Community Medicine

## INTRODUCTION

You are being asked to take part in a research study. This study will only include people who chose to take part.  Please take your time to make your decision.  Please read this document carefully and if you have any questions, please ask the researcher who provided you with this consent. This consent form describes the purpose, procedures, possible benefits and risks of the study.

You are being asked to take part in this study because you are a patient at Christiana Care's Family Medicine Center and your visit today is scheduled with a resident physician.

The person responsible for this study at Christiana Care is: Brian M. Rahmer, Health Services Research Manager in the Department of Family and Community Medicine.

## WHY IS THIS STUDY BEING DONE?

The primary purpose of this study is to learn more about how patient-centered care is being delivered. We do this by observing how you and your doctor communicate with each other during your office visit. Also, what we learn from this study may help us improve how we train and educate resident physicians.

## HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

About 30 people will take part in this study. Participants will be patients of Family Medicine Center resident physicians at either Wilmington Annex or Foulk Road location.

## WHAT IS INVOLVED IN THE STUDY?

No part of your visit with your doctor will be different than normal if you choose to participate in this study. The only difference during your visit with your doctor will be the presence of a video camera, attached to the ceiling of the exam room, which will record your interaction with your doctor.  This camera is capable of recording both audio

**CHRISTIANA CARE HEALTH SYSTEM**
**INSTITUTIONAL REVIEW BOARD**
CCC#     33200                                    Page 1 of 5
**APPROVAL DATE:**      09-18-2013
**APPROVAL PERIOD**     09-18-2013                          Patient Initials:_____
      **THROUGH**     09-17-2014                                Date:_____

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# Appendix C

## ANNOTATED CODING MANUAL FOR INTERACTION ANALYSIS

The Generalized Medical Interaction Analysis System (GMIAS) was originally developed by a team led by M. Barton Laws, Ph.D. then of Latin American Health Institute, under the supervision of Ira B. Wilson, M.D., of Tufts Medical Center, with funding from the Tufts University School of Medicine Faculty Research Fund. Team members were Ylisabith Bradshaw, D.O., of Tufts University School of Medicine; Amanda Barrett, then a master's degree student in health communications at Emerson College and the Tufts University Graduate Program in Public Health; and Michael Immel, an experienced medication adherence counselor.

## SPEECH ACT CODES

**Classification of speech acts:** Speech acts are categorized according to the type of social resource they embody. It is very important, in learning the system, to keep in mind that syntax (grammar) provides only a partial and potentially misleading clue to the nature of a speech act. The speaker's intention must also be understood through the context, including the logic of meaning and the social relations between the parties; non-syntactical cues such as inflection; and the other interlocutor's response, which is influenced by non-verbal cues which may not be available to the coder. As people are normally fluent in these elements of "social grammar," the proper identification of speech acts should not be difficult. However, coders must remain aware of the social context and meaning of the discourse. A single speech act, seen in isolation, cannot be classified. Identical sequences of words, in different contexts, may constitute entirely different speech acts.

**The hierarchical coding structure:** The coding system uses a branched structure with 8 top-level codes represented as integers, (plus codes for missing values), most of which have one or more levels of subdivision. Depending on the investigator's purposes, lower level subdivisions may be used or not. Even where lower level subdivisions are used, they need not be used in all analyses, in other words they can be

"rolled up" to higher levels. A decimal numbering system is used to facilitate this. Some of the categories, in our experience, occur rarely. Some lower level codes are provided principally to permit consistency and comparability with other, extant coding systems, or to provide the coder with exhaustive options.

Also note that ideally the speech act codes would be mutually exclusive and exhaustive when in reality this is next to impossible. Though certain phrases could be interpreted correctly by more than one code, there is always a code that takes higher precedence. A few of the lower-level codes correspond to uncommon speech acts, and are reserved for residual use only. When it is not possible to choose among more detailed codes, use a higher level (i.e., fewer decimals) code to resolve ambiguity.

## Speech Act Code Definitions

**1.0  Asks Question (INTERROGATIVES)**:  The speaker requests that an interlocutor provide information.  While this is often in the grammatical form of a question, it does not have to be, nor are utterances grammatically formed as questions necessarily coded as such.  (Note that a question is also a special case of a directive (5.X), in that it attempts to influence or control the behavior of the interlocutor.)  A rising inflection at the end of a phrase is the most common signal in English that an utterance is a question; this is indicated in our transcription system by a question mark (?).  However, it is possible for this indication to be absent and for an utterance still to be coded as a question.

The code 1.0, *per se*, is never used – a lower level code always applies.  There are two major categories of interrogatives, depending on whether the expected response is a **representative** or an **expressive**.   See below, under Speech Act 2.x, "give information," for a fuller explanation.   Representatives are assertions about intersubjective reality, facts about the world "out there"; expressives are assertions about the speaker's inner state or experience.  One important exception: because reported symptoms are generally treated as factual in medical encounters, they are coded as representatives even though most symptoms are subjectively experienced.

> **1.11     Open question (Representative)**: A broad question without limited response categories, i.e. cannot be answered by "yes/no" or a limited list of choices.  E.g., "How are you feeling?" or "What is troubling you?"  "Where did you spend Thanksgiving?" *Note:* The MIPS distinguishes between "open" and "focused" questions; the latter are said to be about a specific topic.  In our experience, this distinction

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could not be made reliably – questions nearly always have some limitation as to topic. Questions that would be coded as "focused" or "open" in the MIPS are coded as 1.1 in our system.

**1.12    Closed question (R)**: questions that require a brief, specific answer, such as yes or no, a choice of limited options, or simply to specify a number, a color, date, or time, etc. E.g., "Does it hurt there?" "Are you working right now?" "Which meal do you take it with?"

      **1.12.1    Asks Confirmation (Leading question) (R)**: Question that includes a proposed answer. This may or may not be asking for the reiteration or assurance of accuracy of a previously discussed or otherwise known or suspected fact, e.g., "Ok, so then you're almost forty-five years old, right?" or, "What are you taking for that, gangcyclovir?" Note that the phrasing is key. "Are you taking gangcyclovir for that?" is a closed question.

      **1.12.2    Asks Clarification (R)**: Question that asks interlocutor to provide new information to better explain a previous statement which has not been clearly or comprehensively understood, or a check that the question has been heard correctly. E.g., "Do you mean Asian Indian or Native American?" "Did you say thirty?" (vs., presumably, thirteen.) Sometimes this merely takes the form of repeating the question, so as to get confirmation that it was heard correctly.

The entire set is repeated for questions soliciting expressives, including opinions, goals or intentions, and affect. (See below for information about expressives.)

**1.21 Open question (Expressive):**   E.g., "How do you feel about that? "What do you want to do?"

**1.22 Closed question (E)**:   "Do you want to try the Combivir?" "Is that alright with you?"

      **1.221 Asks Confirmation (Leading question) (E)**: "You are looking forward to it?"

      **1.222 Asks Clarification (E)**: [P: I wanna quit.]  D: You what? .

**1.3 Probes for knowledge/ understanding**:  The speaker asks the interlocutor to affirm or demonstrate knowledge or understanding.  This has two forms, which do not parallel the open/closed dichotomy of other interrogatives.

> **1.31 Non-specific form:**  This is merely a request for an affirmation that the interlocutor does or does not understand or know something, E.g. "Do you understand what I just said?"  "Do you know what a retrovirus is?"

> **1.32: Requests demonstration of knowledge:**  The speaker asks the interlocutor to demonstrate knowledge or understanding by stating facts or ideas in the interlocutor's own words.  E.g., "Okay, so tell me what medications you are taking." "Tell me how you are gonna take Atripla?" Note that the context will determine whether this is in fact a request for information (1.11).  In this case, the speaker already knows the answer.

**2.0 Give Information**:  Makes a statement purportedly of fact, including facts about the speaker's state of mind/body or about intersubjective reality.  As with 1.0, code 2.0 *per se* is not normally used.

*External State:* **(REPRESENTATIVES)**

**2.1 Factual Information**:  A statement about any aspect of intersubjective reality.  A fact which is in principle verifiable, a meaningful statement in positivist epistemology.  Also includes doctor's diagnoses when directly observed, as opposed to arriving through deduction, which is 2.12.  For example, "I see thrush there," or "the knee is stable"; and patient's reports of pain or other subjective experience that are represented as symptoms or drug side effects.  Although these may not be directly verifiable, they are treated as factual information for diagnosis, that is physicians normally treat them as representatives, not expressives (see below). Furthermore, the patient's intention is not principally self-revelation, but to provide the physician with information needed to make a diagnosis or prescribe treatment.  (They may be ultimately verifiable in principle in many cases through diagnostic procedures.  A patient with a factitious disorder may be said to be fabricating but then any purportedly factual statement could be a lie.)  Examples: "It hurts when I swallow."  "I was run over by a bus." "I was on Combivir at the time." "I am able to walk to the store." "I heard it on the radio/I saw it on TV."

> **2.11 Behavior**: Statement about the speaker's past or ongoing controlled, intentional behavior or actions.  (Discussion of future behavior is likely to be in the commissive or expressive categories, but see 2.121.)  Example:

"I walk my dogs every morning." "I took my pills this morning." "I always make way for fools." "I walk to the store every day." "I listen to the radio/I watch TV." "So I said to her, 'You can't treat me like that.'" (Note that what the speaker "said to her" is an expressive, but the utterance literally reports the fact that she said it, and hence is a representative.) Statements about involuntary behavior – such as vomiting, diarrhea, inability to fall asleep, a required work schedule, appointment schedule, or regimen schedule, are 2.1.

**2.12 Conclusion or Deduction:** A conclusion, best guess, educated hypothesis; includes previously made deductions. Examples: "These are likely canker sores." "I believe it is benign." In other words, this is an assertion of fact presented as the result of a process of logic or consideration, rather than a simple observation.

> **2.121 Explain/outline determined future course of action** This is used when the speaker describes anticipated future events, but the utterance is clearly not a **commissive** (see codes 6.X), i.e. the purpose of the utterance is not to make a promise or state a newly formed resolve, but merely to describe anticipated reality. E.g., "They're going to close this building for renovations in July/so our offices are moving to 224 Reversack St." "I'm coming in for a biopsy on Tuesday," although it describes the speakers' non-compelled future behavior, is intended to inform rather than to formulate a new resolve, hence it would normally go in this category as well. These can sometimes be difficult to distinguish from commissives. See below, under 6.x, for further discussion.

**2.13 Confirmation:** The speaker affirms that a proposition or hypothesis expressed by the other is true or not true, includes "yes," "no," "uh-huh," "Yes, that's right." This code will also be used if the speaker adds a reiteration of the interlocutor's proposition to which she/he is responding, but does not include any new information. E.g., "No, I haven't met him." However, "I don't know" is a statement about the speaker's internal state [expressive -- knowledge] and "I don't think so" is a deduction (2.12). This speech act follows 1.121, **leading question**, nearly all the time. (Investigators could choose to code negation separately from confirmation, or to leave them as a single category as we have done.)

**2.131 Repetition Agreement**: Speaker repeats the words of previous speaker to confirm that he/she has understood the previous statement.

<u>Examples:</u>

P: and I got neuropathy. (2.1)

D: and you got neuropathy. (2.131)

P: mostly in my feet. (2.1)

**2.132 Finish Sentence for:** speaker finishes previous speaker's sentence so as to express his/her understanding, give confirmation; *However, if finishing the sentence asks question, code as Asks Question*

**2.14 Invocation of shared information:** The speaker announces information which is already known to the interlocutor. This may be done to set up a line of argument, to reminisce, to provoke an emotional response, or for no clear reason. If it is done to influence behavior (e.g. "You know that if you miss doses you risk resistance.") it is a directive, 5.5 – see below. However, without clear contextual evidence that the speaker's main intention is to influence the interlocutor's behavior, such utterances should be coded here, as almost any assertion might be expected to affect the interlocutor's behavior in some way. If it contains an element of criticism or praise of the interlocutor, it should be coded as 2.4x (see below); if it is empathic or clearly intended as reassurance, see 4.x.

*Internal State* **(EXPRESSIVES):** Statement about the speaker's consciousness or mind: knowledge, beliefs, values, attitudes, judgments, desires, goals, and emotions.

**2.2 Comprehension or Knowledge (or lack thereof)**: Statement that explicitly expresses having or not having knowledge. The speaker's intention is not to convey the information to the interlocutor (who may already have it) but rather to demonstrate his/her own possession or lack of possession of the relevant information. Example: "Yes, I'm supposed to take two of these three times a day, with food," in response to speech act 1.32, or simply, "Yeah, I know."/ "I don't know," perhaps in response to speech act 1.31. (Investigators could choose to code having and lacking knowledge separately.)

**2.3 Values, Beliefs, Assumptions**: Permanent or long standing ideological or moral orientation to the world, including culturally determined attitudes and understanding, religious faith, ethical principles.

**2.4 Preferences, Tastes, Opinions**: Personal preferences, likes and dislikes, as they apply to specific objects such as foods, habits, music, specific people or categories of people, the desirability of a certain course of action for another person, including the interlocutor, when not presented as a directive. (The desirability of a course of action for the speaker, however, is 2.5.)

> **2.41 Complain/Criticize:** A negative evaluation <u>of the interlocutor</u>. E.g., "You aren't trying hard enough," "You don't listen to me." Any other negative evaluation, e.g. a complaint about hospital procedures, the pharmacy, or anything else, is a generic opinion (2.4). **Note however**, that if the intention is to influence the interlocutor's behavior, i.e. to discourage it, this is a **directive,** SA 5.71. See below.

> **2.42 Compliment/Praise:** A positive evaluation <u>of the interlocutor</u>. E.g., "You're doing a really good job!" Includes expressions of gratitude, but note that the mere formality of "thank you" is classified under Social Ritual. **Again**, approval intended to reinforce and encourage behavior to continue is a directive, SA 5.7.

> **2.43 Agree with,** and **2.431 Disagree with** apply to agreement or disagreement with tastes and opinions only, not with facts, which is 2.13. Note that for agreement or disagreement to pertain, the tastes or opinions must have the quality of mutual exclusivity. Personal likes or dislikes may differ without implying conflict, e.g. "I like chocolate," "I don't," are expressions of parallel opinion, 2.4, because no contradiction is implied, one does not negate the other. However, "I am a liberal" and "I am a conservative" do constitute disagreement, because incompatible goals for politics and society are implied.

> **2.44**: **Apologize:** An expression of regret or sorrow for an action or oversight by the speaker which is perceived to have harmed or offended the interlocutor.

> **2.45 Validating Opinion:** Speaker indicates agreement with or approval of an expression of distress or concern by the interlocutor. E.g., "Yes, this is a

worrisome issue," "It should be a priority for us to find out what is happening," etc.

2.46 **Negating Opinion:** Speaker indicates that a situation which worries or distresses the interlocutor is not in fact worthy of concern or distress. "This sort of thing is not serious," It's a minor issue."

2.5 **Desire or Goal**: Expressions of what a person wishes to do or to accomplish, intends to do, or wishes to occur. Note that this refers to the speaker's internal state only; a statement that someone else wants something to happen, (e.g., "You wanted to get my viral load down to below 500) is factual information, 2.1. Also, this speech act is easily confused with a commissive (see below.) The statement which formulates an intention to perform a specific behavior or action which is under the speaker's control is a commissive, not an expressive. "I wish I weren't so fat" is speech act 2.5, an expressive, as is "I would like to lose weight." "I am going to exercise ½ hour every day /and stop eating cheese" are commissives. **Note that** physicians sometimes formulate directives as goal statements, e.g., "I'd like for you to take Tylenol." See SA 5.3.

2.51 **Past Desire or Intention**: Statement about an intention to take action or goal/desire/wish had in the past. Example: "I was going to take my pills that morning but my cat threw up in the bathroom." *(Underlined portion only. The example consists of two utterances, the second is 2.1.)* Note that this is again, technically an internal state which is not verifiable but inseparable from information that the intended act was not carried out.

2.6 **Emotion:** Statement about a person's current mood or feelings, or at a specific time in the past. Anger, happiness, sadness, etc. (Some of these may be manifested as interjections, including impolite or taboo words.) There are no clear distinctions or bright lines between some of these emotional states. Distinguishing between concern, discomfort, and sorrow may be difficult; an utterance might contain elements of various of these states. The list is presented so the coder will always have satisfactory options, but for analytical purposes, it is probably sound practice to combine these into broader groupings.

2.61 **Concern/Fear/Anxiety**: Example: "I'm worried that I won't be able to play the piano anymore.*"* Note that this is called a "**cue**" in the MIPS.

2.62 Pain/discomfort: "ouch" "it hurts!" -- but **not** if presented as a symptom.

**2.63** Laughs: laughs

**2.64** Surprise: Expresses surprise: "Holy smoke!"

**2.65** Joy; expresses joy, pleasure, or positive affect: "I'm so happy!" "Whoopee!"

**2.66** Mild satisfaction.  This is more common than 2.65, indicates mere approval – e.g., "good," – rather than strong affect.

**2.67** Sorrow, grief, weeping. (**Not** apology, see 2.64.)

**2.68** Anger/Frustration

**2.69**  Mild annoyance

**2.70** Apathy, submission, fatalism, despair

**2.71** Hope, positive expectation

**2.72** Equanimity: speaker is accepting or stoical in the face of events, including adversity

**3.0  Conversation Management:**  Speech acts which serve to manage either turn-taking or the topic of the conversation.  "Talk about talk."

**3.1 Facilitative utterance:**   A statement which acknowledges that the speaker is listening while continuing to cede the floor to the interlocutor.  Typical examples are "yeah" "aha" "ok" "right" etc.  Although they often correspond to words or sounds which are also used as affirmation or agreement, they do not necessarily imply that the speaker is agreeing, but only that the speaker is listening.  Roter calls these "back channel" utterances.

**3.2 Transitional or Buy-time**: a statement which indicates the speaker will commence talking/take over conversation or continue talking, includes mumbling and stammering prior to stating a better thought-out response.  Classic examples are, "Well now let me see here," "You know," etc.  Also used when the speaker makes an utterance purely for the purpose of seizing the floor, e.g. "Now wait a second; I think that actually might be a good idea."

**3.3 Introduce topic:**  The speaker announces a new topic, e.g. "Now let's talk about . . ."  **Note, regarding codes 3.3-3.5, that most changes of topic do not involve a**

**speech act which specifically marks the change or accomplishes the purpose; people just move on to another subject. This code is for residual use only; do not code any phrase that happens to start or end a topic as such**- for example, if a patient suddenly blurts out, "You know my neck really hurts." This would receive the code 2.1 factual information, not 3.3

**3.4 Close topic:** The speaker announces that the previous topic is finished. Often consists of a single word such as "okay," "alright."

**3.5 Introduce pre-agenda topic:** The speaker introduces a topic which she or he indicates the other interlocutor actually wanted to talk about, e.g., "Now, you wanted to talk about some sores in your mouth?" This information may come from a nurse, receptionist, a previous conversation, a note from another provider, or an unknown source. The point is that it would be misleading to code this as introduction of a topic by the speaker because it is really the other interlocutor who is exercising control of the agenda in this case.

**3.6**: **Acknowledgment:** An indication that the speaker has heard and understood the interlocutor. If the interlocutor holds the floor, this code is not used, rather it is **3.1, facilitative utterance**. However, a speaker will occasionally say "okay," "alright," etc., and then take the floor. If the utterance clearly signals agreement or confirmation, it should be coded accordingly as 2.43 or 2.13. This code is uncommon for most speakers, but some have a habit of frequent acknowledgment.

**3.7 Qualifying Utterance:** An utterance which serves to put a gloss on a subsequent utterance, define its social appropriateness, express reservations about saying it, express happiness about being able to say it, etc. Examples are, "I probably shouldn't tell you this, but . . . " "As you probably already know …" "I'm sorry to have to mention it, but . . . "As I always say . . ." "I hate to say this . . . " "I could be wrong, but . . . " "I'm happy to say that --" **Note:** This is a separate speech act even though it may grammatically part of a larger clause. "I'm sorry to say that your test was positive," if taken as a single speech act, would have to be coded as an expressive; but the point is to convey the information that the test was positive. Therefore this is two speech acts:

  3.7                                 2.1

I'm sorry to say that / your test was positive

**4.0 Empathy/Reassurance**:  A statement expressing an empathic response to the interlocutor's emotions, concerns or feelings, validating those feelings, or attempting to soothe or assuage negative emotions.  Example: "I'm sorry for your loss," "I feel terrible for you."

**4.1**: Validates feeling:  The speaker indicates that an affective state expressed by the interlocutor is appropriate, understandable, or is to be expected; or non-judgmentally affirms empathy or shared distress over that state.  Examples: "I can certainly understand why you feel that way," "Yes, you must be concerned," "Of course you are worried about that," "Oh, I know how you must feel."

**4.2 Negates feeling:**  The speaker indicates that an affective state expressed by the interlocutor is unwarranted or uncalled for, in an apparent effort to reassure.  "Oh, this is nothing to worry about," "It's really not a problem."

This is a category of expressive, but we have given it a separate top level code because it is seen as very important in other systems.  Note, however, that we reserve this code exclusively for utterances which overtly have the purpose of expressing empathy or reassurance.  Information which happens to be reassuring (e.g., "you should get over this in a couple of days with no lasting ill-effects.") is still just information.  The truth could happen to be discouraging, but that is not the speaker's option and is not a measure of the speaker's communication style.

Note that a 4.0 utterance may occur in conjunction with a representative or commissive.  E.g., "Don't worry/this condition isn't serious."  "Don't worry" is code 4.0, "This condition isn't serious" is 2.1.

Also note that 4.0 is not to be confused with 5.7 Approve of/Encourage. The 5.7 code applies to utterances that have a directive intention (attempting to influence other interlocutor's behavior) and are not merely providing emotional support.

**5.0 Urge Action (DIRECTIVES):** A statement that serves to control or influence the behavior of the interlocutor; may be phrased or framed in the following manners:

**5.1 Recommend/suggest:**  Couched so as to suggest it is the speaker's advice, not necessarily an order or request.  E.g, "I think you should consider taking ritonavir," "Why don't you try acupuncture?"

**5.2 Request:** A direct request for other speaker to do something, Example: "Could you write my supervisor at work a letter?"

**5.3 Directive Aspiration/Aim**: Examples: "I'd like to see you take your pills more regularly." "I want you to call me in two days to let me know how you are." "I want you to go down to the lab for a blood draw/ and come back in two weeks." Note: Although the phrasing seems to be that of an expressive – i.e., the speaker is expressing a wish – it is clear that in the social context of a medical encounter, when a physician expresses such a desire the intention is to direct the interlocutor to carry out the physician's expressed desire. In other words, this is simply a polite way of giving "doctor's orders." Such utterances should not be coded as 2.5, "Desire, Goal, Intention," because the intent is not to describe the speaker's wishes but to cause the interlocutor to carry them out. However, "I'd like to see your viral load go down" could be 2.5.

*Note that the distinctions among 5.1, 5.2 and 5.3 are not terribly important.*

**5.4 Direct/Mandate:** An utterance in grammatical command form. Examples: "Take two pills three times a day." "Ask them to switch your hours." Note that this speech act frequently occurs in the process of physical examination. "Get up on the examination table," "Say ahh." Remember that the topic codes will clarify the context.

**5.5 Convince:** Speaker presents an argument intended to overcome the interlocutor's reluctance to take a desired action. "You really need to do this." Note that this may include utterances which are also representatives, e.g., "If you don't take antiretrovirals you will get sick very quickly." If the context shows that a) the interlocutor already knows this, or knows that the speaker believes it and b) such utterances are clearly part of a directive strategy, the directive code takes precedence. Note that in this context, the information or deduction/opinion is not new to the interlocutor; rather it is being marshaled as part of an argument. In other words, the speaker is not giving information, but invoking it for directive purposes.

**5.6 Give permission**: Yes, this is a directive, because it implies that the speaker controls the interlocutor's behavior. Note the converse, 5.61, if in doubt.

**5.61 Refuse permission**

**5.7 Approve of/Encourage** and **5.71 Disapprove of:** The speaker reinforces or discourages an action the interlocutor has indicated she/he intends to take or has already taken. Note that this must have directive intent, to encourage the continuation or cessation of a behavior.

**6.0 Indicate/Confirm Action (COMMISSIVES):** Utterances in which the speaker makes a promise or resolves to take action.

**6.1 Ask permission to do**:  Includes asking permission to conduct physical examinations, venipuncture, or otherwise invade the interlocutor's personal integrity

> **6.12 Expose current intention:** Explain physical exam related actions/events that will be undergone. "We'll go from head to toe."  "Now I'm just going to press on your abdomen."  This is only used within topic code 3.1 (see below).  (Although this is conceptually similar to 2.121, we found it convenient to separate it for analytic purposes; unlike most speech acts coded in 2.121, this directs the interlocutor to permit an invasion of personal space or bodily integrity which is normally not allowed to people other than physicians.)

**6.2 Commit to Action**: Statement that makes a commitment to do something, a promise to do something. "I will follow through on that right after you leave."  A commissive is defined by the creation of a social obligation to carry out the stated intention.  Normally this is a commitment in the interlocutor's interest, but it would not have to be. "I'm going to sue you" would likely be a commissive.  A physician outlining a future course of treatment, however, is normally not a commissive but merely a prognostication, 2.121, unless there is an element of social obligation, e.g., "I promise we'll get you into surgery before Tuesday."  An utterance which merely describes an existing intention, without creating a new resolve or commitment, is also 2.121, a representative.

> **6.21 Agree to do** and **6.22 Refuse to do:** Commissives in response to a corresponding directive.

**6.3 Offers to do:**  Proposes to act or commit to action if the interlocutor so desires. "I'll prescribe Vicodin if you like."  May be phrased as a question, "Would you like me to [do something]?"

**7.0 Humor, Joke, or Levity:** brief humorous narratives or comments, intended to provoke laughter, or simply light-hearted jovial additions to conversation. *Note that this code should be used residually, only when using another code would be misleading.*   For example, "Why did the chicken cross the road?" is not truly an interrogative.  Irony, sarcasm, humorous exaggeration may belong here if the main intent is levity, but if the statement nevertheless expresses a real sentiment it

should be coded as the appropriate expressive.  Most sarcastic statements are actually an indirect way of expressing an opinion or a desire, and should be coded as 2.4 or 2.5.  Some representatives may also be expressed humorously.  E.g., "Is the Pope Catholic?" means "yes," may simply signal agreement with a proposition, and should be coded as 2.1 or 2.13, or in the appropriate expressive category.

**8.0 Social Ritual**: Expressions such as "hello", "goodbye", "thank you", "nice to meet you" -- politeness words, mere formalities.  Includes common ritual utterances such as "Merry Christmas" and "Happy New Year", "have a nice day", etc., which are not sentiments especially reserved for the interlocutor.  Note that apology is covered as a representative, but "sorry" might be coded here if it is truly inconsequential.  If "I'm so sorry" or a similar formulation is intended not as apology, but as empathy, it should be coded as such.

**Note:** In Speech Act Theory, utterances which have the formal effect of changing social reality are called performatives.   These generally occur in ritual contexts, and the pronouncements are made by specifically empowered persons such as judges or priests.  E.g., "I now pronounce you man and wife," "I find the defendant not guilty," "I hereby confer on you the degree of Doctor of Humane Letters," etc.  Diagnostic labeling by a  physician can be viewed as such performative, at least under certain circumstances.   Investigators who are interested in that sociological idea could create an appropriate code, but in the system as currently structured, delivering a diagnostic opinion would be a representative act.

**Missing Value codes.**

**81 Data Missing**:  Words on tape cannot be understood. Marked by [#W], [Unclear]P, or [Unclear ]ROS; code as Data Missing unless the coder is confident that he/she can deduce what type of speech act it is.  [Individual investigators may decide what level of certainty is required to code a doubtful instance.]

**82 Incomplete utterance**:  Expressions not fully formed - speaker begins a thought but does not finish it, the intent cannot be divined.

> **82.1 Interruption**: When speaker is obviously cut off by another speaker and the intended meaning cannot be divined.

**83 Coder Doesn't Know**:  coder unable to assign code, perhaps because the utterance appears to make no sense or is too ill formed, needed context is unavailable due to missing data, or the situation simply cannot be inferred from the data.

**99 Out of universe:** An utterance which is not a speech act (E.g., patient says "ahhh" to allow physician to view the throat); transcriptionist's comments, stage directions; or speech unrelated to the medical encounter that happens to be on the tape.

**11 Continuation of a previous segment**

If a speech act is interrupted by an interpolation by either the speaker or the interlocutor, and then completed, the first portion should be coded and the second given the code of 11, to indicate that it is part of the previous speech act.

<u>**Topic Codes**</u>

Topic codes are specific to the research questions of interest in a given study. However, the system is designed so that broad elements typically found in medical visits are represented by broadly defined, high-level codes. To the extent possible, these correspond to categories found in the Roter and MIPS systems. For a particular study, investigators can then "roll up" the lower-level codes in areas of less interest to more general, high-level codes, and "unpack" codes in areas of greater interest to any desired level of detail. By maintaining high-level codes consistently across studies, comparison becomes possible of the total percentage of utterances devoted to broad areas, and, if it is relevant, of patterns of speech acts within those areas. At the same time, investigators do not have to spend development effort or coder time on detailed coding of content in areas of less interest, and can focus on whatever specific content-related questions they like with complete flexibility.

<u>**Topic Code Definitions:**</u>

**1.0 Physical Health/ Global Health:** discussion about general health issues**.** Note that in everyday life, "How are you?" and its innumerable variations on first meeting are mere pleasantries. However, when a physician greets a patient in this way it may elicit a substantive reply. In that case we code this standard introductory colloquy as 1.0, rather than 4.0 ("socializing"). If the patient answers this as a pleasantry, e.g. "Fine, and you?" and the physician responds accordingly, then it should be coded as 4.0. Of course, an ensuing extended discussion of the **physician's** well-being would be coded as 4.0.

**1.1 Specific Illness:** discussion about particular disease entities, syndromes, or symptoms, including HIV-related illness. Usually one of the subsidiary codes is used; 1.1 *per se* is rare.

**1.11 Treatment:** discussion about treatment of disease. This is a structural element, but is seldom used because more specific codes are usually available.

**1.111 Pharmaceutical:** discussion about pharmaceutical treatment (any discussion of medications, whether ARVs or not), includes everything: risks, benefits, side effects, adherence, viral drug resistance, stigma. Also includes non-allopathic medications such as herbals, homeopathy, Chinese, Ayurvedic. Again, this category is seldom used – only the following sub-categories are used in practice.

**6.1 Prescription opioids**: As above, if the drug happens to be an opioid. **Not, however, maintenance drugs for addiction recovery** such as methadone or suboxone, which are coded under the "Recovery" psychosocial category (see below), or opioid abuse, coded under addiction.

**7.0 Non-allopathic treatment (renumbered from 1.1113)** Chemical or biological entities (such as herbs), procedures or rituals, such as Reiki therapy or faith healing, intended to treat disease, not specifically approved or recommended by an allopathic practitioner. Procedures of unclear status, such as acupuncture or chiropractic, are coded here or under non-pharmaceutical treatment depending on whether the doctor appears to believe they are appropriate or efficacious.

**8. 0 Non-pharmaceutical treatment (renumbered from 1.114):** discussion about non-pharmaceutical treatment such as nutritional support, acupuncture (if approved by the physician), physical therapy, exercise regimens, meditation, oxygen, surgery, etc., if recommended, prescribed or approved by an allopathic practitioner.

**1.12 Diagnosis:** discussion, predictions, or conclusions about whether a patient has a specific disease or disease or pathological state. Also includes the aftermath of surgery and assessment of recovery/healing processes (Example=discussion about appearance and progress of skin where benign cyst was removed)

**1.14 Symptoms, Complications, History:** discussion of symptoms and complications perceptible to the patient, and information of diagnostic relevance such as possible exposures, illness among household members, travel, etc. Not to be confused with diagnosis (which means coming to a

diagnostic conclusion) or disease counts. Includes comparisons between symptoms then and now.

1.15 **Other diagnostic or prognostic tests or procedures:** Blood tests not directly related to HIV disease, such as blood lipids, blood counts, liver enzymes, etc. Note that these could be related to side effects of HIV treatment or symptoms of HIV disease, but only the tests specified under 1.13 are included there. Also, imaging, endoscopy, etc., except for clinical examination during the encounter, which is 3.1. Note that this does not normally include diagnostic conclusions based on the procedures, which would be 1.12. Basic observations using instruments commonly available in an outpatient examining room, such as a sphygmamometer or otoscope are coded as 1.14.

1.16 **Risk behaviors**. Sexual, dietary (other than prescribing specific supplements for specific conditions, which is 6.0), tobacco, sedentarism, riding a motorcycle without a helmet, advice to exercise or lose weight for prevention purposes (as opposed to treatment of an existing condition such as diabetes). Because it has implications beyond direct effects on health, alcohol and other drug abuse or addiction, other than tobacco, is placed in the psycho-social category, 2.X. (See below.) Nevertheless drug abuse harm reduction, such as advice against needle sharing, which does not touch upon reducing or stopping use, is still coded here.

1.17 **Prevention:** screening, vaccination, prophylaxis, other than patient's behavior which is 1.16. Note that coders must understand the distinction between procedures done for diagnosis, and for screening. Mammography, for example, or PSA testing, could go here or under 1.15.

1.18 **Prognosis/anticipatory guidance:** Discussion about the likely future course of disease, future state of health, consequences for functioning or symptomatology, and possible future interventions.

1.2 **Reproduction:** Includes the patient's own pregnancy, attempt to get pregnant or fertility treatment, discussion of possible risks of pregnancy (e.g., HIV transmission to baby); also fertility and fertility treatment for men. The health of an already born baby is under 2.5.

2.0 **Psycho-social**: Dr. and patient discuss patient's psychosocial problems or related services such as substance abuse and treatment, family problems, finances,

homelessness, etc.  As with 1.0, what might be pleasantries in other contexts – such as discussion of family and friendship relationships – may go here, most often specifically under 2.4.

**2.1 Recovery**:  discussion about substance abuse recovery or substance abuse programs in which patient participates if patient is currently in recovery.

**2.2 Substance Abuse**: discussion of any substance abuse other than tobacco: Alcohol, Heroin, etc. if individual is not in recovery or has relapsed.

**2.3  Mood or emotions** (**not** DSM diagnoses or psychiatric disorders, which are coded as appropriate in the biomedical domain.)

**2.4 Relationships** Family, friends, co-workers. However, if there is no contextual evidence that there are concerns about social isolation, family problems or conflicts, etc., such discussion could be mere pleasantry and coded under 4.0.

**2.5 Health of significant others**.  May be general discussion of other people's health, or patient asking for specific medical opinion about other people.

**2.6 Social Services.**  Discussion about non-medical support services other than addiction treatment, such as support groups, case management, homemaker services, and counseling other than mental health treatment.

**2.7 Other psycho-social stressors**: Criminal justice involvement, workplace or employment problems, homelessness, discrimination, neighborhood conditions, etc.

**2.8 Religion/spirituality:**  If discussed specifically as a source of support or distress.

**2.9 Health insurance/payment for health care:**  Lack of insurance, co-pays, deductibles, out of pocket expenses as financial stressors or sources of anxiety for the patient.  An inconsequential or non-stressful issue about, for example, which drug is in a covered formulary or insurance affecting the timing of a procedure belongs in 3.0 or 3.3, however.

**3.0 Logistics:** logistics of provision of medical services including appointment-making, getting blood drawn, tests, lab results, medical records, insurance status, referrals, etc. Example: Dr. forgot her stethoscope, Dr. is late, patient is late, need to fill out forms,  can't afford to pay for services, parking problems, etc.  The essential distinction is that these topics are not within the biomedical domain.

**3.1 Physical Exam:** speech related to physical task of carrying out exam, e.g. "take a deep breath", "lie back," etc. *Does not* include discussion of symptoms, diagnosis, or observations made by the physician of clinical findings during the exam, which normally belong in the diagnosis/prognosis category. E.g., "Open wide," "say ahhhh" do go here. "Looks like thrush" does not. Note that this topic is often interspersed with talk about other matters. Topic codes often switch frequently between 3.1 and other subjects. Just because the physical exam is ongoing does not mean that most talk which occurs during that time receives this code.

**3.2 Studies/clinical trials:** Discussion of studies in which the patient is enrolled, or may wish to enroll. This only applies to logistics of studies, decision making about enrollment, study procedures, risks, etc. Information that happens to be derived from a study protocol that then enters into the patient's diagnosis or treatment is coded under the appropriate categories just like any other medically relevant information.

**3.3 Pharmacy/refills:** Patient's need for prescription refills, difficulty getting prescriptions filled, difficulty paying for medications, etc. **If they cause stress or financial difficulties, they should be coded under 2.9**. This code only applies when there is no perceivable relationship to medication adherence, or to psychosocial stress.

**3.4 Certifications:** Providing physician certifications or required letters for benefits, such as disability, medical transportation, home-delivered meals; employment (e.g. as a driver, pilot, firefighter etc. that require medical clearance); excuses from work; or similar documents.

**4.0 Socializing**: Dr. and patient engage in social ritual or conversation unrelated to medical purpose of encounter. This is a residual category. General inquiries about well-being, family and friends, work, recreation, etc. which are common topics of casual social conversation in daily life and do not appear to concern psycho-social issues of possible relevance to medical care may belong here, but doubt should be resolved by coding in the appropriate psychosocial (2.x) category. Talk about sports, weather, politics, etc., would belong here.

**4.1 Physician/patient relationship**: Overt discussion of the interpersonal relationship between physician and patient, including assertions of gratitude for the relationship, and discussion of its qualities such as trust, mutual regard, collaboration or conflict.

**4.2 Physician self-disclosure or boundary violations**.  This refers to physician self-disclosures which are not of evident relevance to providing the patient with medical services or reassurance, and go beyond the normal disclosures of small talk.  Physicians may state that they have undergone a procedure so as to reassure the patient that it is safe or endurable, which we do not necessarily consider a self-disclosure but would code in the appropriate treatment domain.  An affirmation in response to a question that the wife and kids are doing fine would simply be coded as 4.0.  However, an extended story about the physician's own health or health care, or family troubles, could be coded here.  Patients can also engage in or initiate boundary violations, for example by flirting with the physician or soliciting or encouraging inappropriate physician self-disclosure.

# Appendix D

## VIDEO-ELICITATION INTERVIEW GUIDE

**Physician interview guide used during video elicitation interviews.**

**PHYSICIAN PARTICIPANT No._____**          **Interviewer: _____**

**Date: _____/_____/_____  _**                    **Location: _____**

**Before you start, please describe any special or unusual circumstances regarding interview:**

**Introduction:** In my research, I am interested in learning how doctors and patients communicate with each other within a patient centered medical home.  As you watch the video of your recent patient encounter with *your diabetic patient*, I would like for you to think about the strategies and tools you use in helping your patient in terms of communication strategies, care plans and reaching goals. You may want to comment on how you prioritize your visit agenda relative to other competing demands, such as medication refills, lifestyle activities, care for other family members, or other non-prevention activities. Also, I would like for you to think about and comment on any barriers or facilitators to patient-centered care, both personal and institutional.

| Question Goal | Sample Question |
|---|---|
| Identification of patient-centered care strategies | As we review your visit with your patient, please be aware of any elements of care that you might perceive as being "patient-centered" in nature. When you notice "patient-centered care" being performed, please pause the video and/or ask me to pause the video. |
| Thoughts, beliefs, and emotions | What were you doing/trying to do at this point in the visit? What makes this moment in particular stand out to you? How did you want the other person to perceive you? |
| Impressions of others | What did you think the patient was thinking about you at this point? What were your impressions of the patient's actions at this point? Why do you think the patient made that statement at this moment? |
| Impressions of self | What do you notice about your actions at this point? What about your behavior at this point surprises you? |
| Decision | What let you know that was the right decision to make at this point? |

| Question Goal | Sample Question |
|---|---|
| making processes | What information did you use in making this decision? What other courses of action were you considering or were available to you? What made you decide this was the right decision at this point in time? How much time pressure did you feel in making this decision? |
| Barriers and Facilitators *Addressed at commencement of the recorded interaction or when the resident asks to stop.* | How pleased are you with the outcome(s) of that visit? Do you feel you reached your goals for that visit? What about the patient's goals Did you have the resources to meet your patient's needs? How supported do you feel in delivering patient-centered care? Is meeting the goals of the patient a priority in your practice? What elements of your practice support your ability to provide patient-centered care? What changes would you make to your practice in order to be more patient-centered? |

**DEFINITIONS OF TERMINOLOGY**

**Access:** The ability to obtain needed medical care. Access to care is often affected by the availability of insurance, the cost of the care, socio-economic and cultural inequities, and the geographic location of providers (LaVeist, Pollack, Thorpe, Fesahazion, & Gaskin, 2011; Robert & Booske, 2011).

**Accountable Care Organization (ACO):** A network of health care providers that band together to provide the full continuum of health care services for patients. The network would receive a payment for all care provided to a patient, and would be held accountable for the quality and cost of care. Proposed pilot programs in Medicare and Medicaid would provide financial incentives for these organizations to improve quality and reduce costs by allowing them to share in any savings achieved as a result of these efforts (Longworth, 2011).

**Chronic disease:** A health problem that goes away and comes back, or that lasts your whole life, such as diabetes, asthma, or high blood pressure. Chronic diseases are usually preventable by adhering to healthy lifestyle behaviors, and are generally manageable with adherence to chronic disease management goals, medication, and healthy habits (Koopman et al., 2003; Wagner & Groves, 2002).

**Chronic disease management:** The coordination of both health care and supportive services to improve the health status of patients with chronic conditions, such as diabetes and asthma. These programs focus on evidence-based interventions and rely on patient education to improve patients' self-management skills. The goals

of these programs are usually to improve the quality of health care provided to these patients and to reduce costs (Ackerman & Mirel, 2010).

**Co-insurance:** A method of cost-sharing in health insurance plans in which the plan member is required to pay a defined percentage of their medical costs after the deductible has been met (Politi et al., 2014).

**Co-payment:** A fixed dollar amount paid by an individual at the time of receiving a covered health care service from a participating provider. The required fee varies by the service provided and by the health plan (Politi et al., 2014).

**Comparative Effectiveness Research:** A field of research that analyzes the impact of different options for treating a given condition in a particular group of patients. These analyses may focus only on the medical risks and benefits of each treatment or may also consider the costs and benefits of particular treatment options (Garber & Tunis, 2009).

**Cost Containment:** A set of strategies aimed at controlling the level or rate of growth of health care costs. These measures encompass a myriad of activities that focus on reducing overutilization of health services, addressing provider reimbursement issues, eliminating waste, and increasing efficiency in the health care system (Hermer & Brody, 2010).

**Cost Shifting:** Increasing revenues from some payers to offset losses or lower reimbursement from other payers, such as government payers and the uninsured (Frakt, 2014).

**Cost Sharing:** A feature of health plans where beneficiaries are required to pay a portion of the costs of their care. Examples of costs include co-payments, coinsurance and annual deductibles (Baicker & Goldman, 2011).

**Deductible:** A feature of health plans in which consumers are responsible for health care costs up to a specified dollar amount. After the deductible has been paid, the health insurance plan begins to pay for health care services.

**Electronic Health Record/Electronic Medical Record:** Computerized records of a patient's health information including medical, demographic, and administrative data. This record can be created and stored within one health care organization or it can be shared across health care organizations and delivery sites (Holroyd-Leduc, Lorenzetti, Straus, Sykes, & Quan, 2011).

**Employee Retirement Income Security Act of 1974 (ERISA):** Legislation enacted in 1974 to protect workers from the loss of benefits provided through the workplace. ERISA does not require employers to establish any type of employee benefit plan, but contains requirements applicable to the administration of the plan when a plan is established. The requirements of ERISA apply to most private employee benefit plans established or maintained by an employer, an employee organization, or both (Snyder, 1975).

**Federal Poverty Level (FPL):** The federal government's working definition of poverty that is used as the reference point to determine the number of people with income below poverty and the income standard for eligibility for public programs. The poverty guidelines, released by the U.S. Department of Health and Human Services (HHS), are used to determine eligibility for public programs and subsidies. For 2014, the federal poverty guideline is an annual income of $23,850 for a family of four (Gaskin et al., 2014).

**Federally Qualified Health Centers (FQHC):** Safety net providers such as community health clinics and public housing centers that provide health services

regardless of the ability to pay and are funded by the federal government (Lewin & Altman, 2000).

**Fee-for-Service (FFS):** A traditional method of paying for medical services under which doctors and hospitals are paid for each service they provide. Bills are either paid by the patient, who then submits them to the insurance company, or are submitted by the provider to the patient's insurance carrier for reimbursement (Brecher & Rose, 2013).

**Health care:** The prevention, treatment, and management of diseases and injuries, as well as the preservation of mental and physical health, through services offered by trained and licensed professionals (like doctors, nurses, dentists, and psychologists, and social workers).

**Health care reform**: A general term for the major health policy changes put in place by the federal Affordable Care Act and any state laws passed to put it in place.

**Health Information Technology (HIT):** Systems and technologies that enable health care organizations and providers to gather, store, and share information electronically (Buntin, Jain, & Blumenthal, 2010).

**Health Information Technology for Economic and Clinical Health (HITECH) Act:** Enacted under Title XIII of the American Recovery and Reinvestment Act of 2009 (Public Law 111–5), the United States Department of Health and Human Services is spending $25.9 billion to promote and expand the adoption of health information technology (Foldy, 2014).

**Health insurance (also referred to as "coverage" or "plan"):** A contract that requires your health insurance issuer to pay some or all of your health care costs in exchange for a premium you pay (Rivlin, 2013).

**Health Insurance Marketplace(s) formerly Health Insurance Exchange(s)**:
State- or federally run and regulated markets where individuals can shop, compare, and buy health insurance coverage (Lang, Cragin, Raymond, & Kane, 2014).

**Health Insurance Exchange (HIE/HIX):** A purchasing arrangement through which insurers offer and smaller employers and individuals purchase health insurance. State, regional, or national exchanges set standards for what benefits are covered, how much insurers charge, and the rules insurers must follow in order to participate in the insurance market. Individuals and small employers select their coverage within this organized arrangement (Haeder & Weimer, 2013).

**Health Insurance Portability and Accountability Act of 1996 (HIPAA):** Through The Health Insurance Portability and Accountability Act of 1996, individuals in many states who lose group health coverage after a loss of employment have access to coverage through high-risk pools, with no pre-existing condition exclusion periods. HIPAA also sets standards that address the security and privacy of personal health data (Ness & Joint Policy Committee, 2007).

**High-Deductible Health Plan:** Health insurance plans that have higher deductibles (the amount of health care costs that must be paid for by the consumer before the insurance plan begins to pay for services), but lower premiums than traditional plans (J. White, 2013).

**Managed Care:** A health delivery system that seeks to control access to and utilization of health care services both to limit health care costs and to improve the quality of the care provided. Managed care arrangements typically rely on primary care physicians to act as "gatekeepers" and manage the care their patients receive.

**Medicaid:** Enacted in 1965 under Title XIX of the Social Security Act, Medicaid is a federal entitlement program that provides health and long-term care coverage to certain categories of low-income Americans. States design their own Medicaid programs within broad federal guidelines. Medicaid plays a key role in the U.S. health care system, filling large gaps in the health insurance system, financing long-term care coverage, and helping to sustain the safety-net providers that serve the uninsured.

**Medical Home:** A health care setting where patients receive comprehensive primary care services; have an ongoing relationship with a primary care provider who directs and coordinates their care; have enhanced access to nonemergent primary, secondary, and tertiary care; and have access to linguistically and culturally appropriate care.

**Medicare:** Enacted in 1965 under Title XVII of the Social Security Act, Medicare is a federal entitlement program that provides health insurance coverage to 45 million people, including people age 65 and older, and younger people with permanent disabilities, end-stage renal disease, and Lou Gehrig's disease.

**Out-of-Pocket Costs:** Health care costs, such as deductibles, co-payments, and co-insurance that are not covered by insurance. Out-of-pocket costs do not include premium costs (Yegian, Dardess, Shannon, & Carman, 2013).

**Patient Protection and Affordable Care Act PPACA:** On March 23, 2010, President Obama signed the PPACA into law as Public Law 111-148, commonly referred to as the ACA or "Obamacare" (Congress, 2010).

**Patient-Centered Outcomes Research Institute (PCORI):** PCORI is an independent, non-profit organization created by Congress in 2010. Its mission is to

fund research that will provide patients, their caregivers and clinicians with the evidence-based information needed to make better-informed healthcare decisions (Sox, 2012).

**Patient-Centered Outcomes Research Trust Fund (PCORTF):** The PCORTF was authorized by Congress as part of the Patient Protection and Affordable Care Act of 2010 in order to fund PCORI. It receives income from two funding streams: the general fund of the Treasury and a small fee assessed on Medicare, private health insurance and self-insured health plans (Reichard, 2011).

**Population Health:** The health outcomes of a group of individuals, including the distribution of such outcomes within the group (Wilkinson & Pickett, 2006).

**Public Health**: All organized measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole. Its activities aim to provide conditions in which people can be healthy and focus on entire populations, not on individual patients or diseases (Turnock, 2011).

**Premium:** The amount paid, often on a monthly basis, for health insurance. The cost of the premium may be shared between employers or government purchasers and individuals (Mills, Engelhard, & Tereskerz, 2010).

**Premium Subsidies:** A fixed amount of money or a designated percentage of the premium cost that is provided to help people purchase health coverage. Premium subsidies are usually provided on a sliding scale based on an individual's or family's income (Paringer, 2013).

**Preventive Care:** Health care that emphasizes the early detection and treatment of diseases. The focus on prevention is intended to keep people healthier for longer, thus reducing health care costs over the long term (Parkinson, 2008).

**Primary Care**: Health services that cover a range of prevention, wellness, and treatment for common and chronic illnesses through long-term relationships with patients. Primary care addresses a wide array of health issues and may coordinate care with specialists (Sandy, Bodenheimer, Pawlson, & Starfield, 2009).

**Primary Care Provider (PCP):** A provider, usually a physician specializing in internal medicine, family medicine, or pediatrics (but can also be a nurse practitioner, physician assistant or even a health care clinic), who is responsible for providing primary care and coordinating other necessary health care services for patients (Starfield et al., 2005a).

**Resource-Based Relative Value Scale (RBRVS):** A system for describing, quantifying, and reimbursing physician services relative to one another. The RBRVS incorporates three components of physician services - physician work, practice expense, and professional liability insurance (Hsiao, Braun, Becker, & Thomas, 1987; Zismer, 1999).

**Safety Net:** Health care providers who deliver health care services to patients regardless of their ability to pay. These providers may consist of public hospital systems, community health centers, local health departments, and other providers who serve a disproportionate share of uninsured and low-income patients (Hock, Ornato, Cosby, & Franck, 2005).

**Single-Payer System:** A health care system in which a single entity pays for health care services. This entity collects health care fees and pays for all health care costs, but is not involved in the delivery of health care (Adler Channick, 2009).

**Social Determinants of Health (SDOH):** The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of

money, power and resources at global, national and local levels (Marmot &
Wilkinson, 2005).

**Specialist**: A clinician who has extra training in a certain medical field, such as
an orthopedist (for bones) or a cardiologist (for your heart) (Starfield, Shi, Grover, &
Macinko, 2005).

**Triple AIM:** The Triple Aim is a framework developed by the Institute for
Healthcare Improvement (IHI) that describes an approach to optimizing health system
performance. The three critical elements of the Triple AIM include improving the
patient experience of care (including quality and satisfaction); improving the health of
populations; and reducing the per capita cost of health care (Berwick et al., 2008a).

**Value-Based Purchasing (VBP)**: Linking provider payments to improved
performance by health care providers. This form of payment holds health care
providers accountable for both the cost and quality of care they provide. It attempts to
reduce inappropriate care and to identify and reward the best-performing providers
(Tompkins, Higgins, & Ritter, 2009).