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INTRODUCTION

Value in healthcare can be defined as the balance between patient-centered outcomes, and services utilized and costs incurred (1). The 'best value' for care means the patient achieves health, or a predetermined functional goal, within a system that provides the 'right' or appropriate service in a cost-effective and efficient manner. Value for patients needs to be meaningful, while providers value care aligned with their mission and training (2). Patients and providers alike support "humanism"; that is care that is compassionate and collaborative (3). The inherent challenge is in the complex nature of our current system, and seemingly non-synergistic efforts of key stakeholders – regulators, payors, and providers. At the very least, efforts toward 'value' may be yielding varied results.

This monograph will explore the delivery of healthcare from a value perspective. Are value-oriented payment models successful in providing better and cost-efficient care? Bundled (procedure-based), capitation (population-based), and value-based purchasing are the most common 'value' oriented payment models. The function of each model, including the traditional fee-for-service, will be described, along with positive and negative results thus far.

Value will then be portrayed through three unique focus groups. How is value-based care defined by stakeholders, including consumerpatients? Focus groups were designed to include high risk individuals (based on ethnicity, gender, socioeconomic or geographic location), as well as caregivers (community health workers). The face-to-face discussion groups were conducted to identify the real-life experiences, values and needs of individuals, as they use the healthcare system. Surveys, studies and reports were reviewed to provide an overview of practitioner/provider and institutional values.

Finally, are the values of patients, providers and organizations aligned to provide ideal care? If not, do the experiences of stakeholders at this moment in time give us a way forward to achieve better, ideal care? This monograph is intended for those interested in an overview of the concept of 'value' in healthcare, how value is operationalized in payment models, and results via real-life patient experiences.



SECTION 1 TRANSITIONING from FEE-for-SERVICE to VALUE-BASED CARE & MODELS

A Brief Explanation of Healthcare Organizations, Payors, Payment Models and Approaches to Care

At the outset of this discussion, it may be worth noting a few points. First, healthcare organizations may use one or more 'payment models' to fund how they provide patient services. The payment models used are driven by the <u>source</u> of funds. Funds or reimbursements come from a federal/government program, such as the Centers for Medicare and Medicaid Services (CMS); a health insurance network, such as managed care (MCO) or preferred provider (PPO), or from an insurance company. CMS continues to aggressively pursue initiatives, models and programs that tie provider payments to value or defined metrics (4). Since CMS funds approximately two-thirds of health expenditures (33% hospitals, 20% physicians & clinical services, 10% retail prescription drug), it is acknowledged as a primary driver of how healthcare services are reimbursed (5).

Healthcare organizations include hospitals, urgent care centers, ambulatory/outpatient surgery centers, physician offices or networks and so on. For example, an outpatient surgery center may receive funds from a variety of sources. The surgery center may be part of a PPO, and may also serve Medicare patients, as well as privately insured individuals. Reimbursement therefore is derived from the federal government (CMS), the PPO and the private insurance company. For the surgery center to receive reimbursement for the care provided to each type of insured patient, the center may have multiple payment models in place to meet the requirements of each reimbursement/payor entity.

Healthcare organizations have created or adopted 'approaches' to delivering patient care, or patient care models. The goal and approach can be philosophically based, from traditional to patient centered to holistic. To illustrate, an Accountable Care Organization (ACO) represents an organizational mission and network; a network of practitioners/providers and payor(s) who agree to manage and coordinate care with a goal to provide quality care and decrease costs. Often, the care approach encompasses the need to receive reimbursement from the payors. The approach to patient care or care model may be the same as the payment model, but they can also be different. 'Value-based' is a term used for both patient approach or care model, as well as a payment model.

For about the last decade, the delivery of healthcare has been challenged with moving from a traditional fee-for-service reimbursement system, to one that is value-based. This monograph will discuss the characteristics of the fee-for-service and value-based payment models, the healthcare environment or challenges created by them, and juxtapose those models with consumer-patient experiences and values.

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Fee-for-Service Payment Model – What is Working, What is Not

Fee-for-service is the traditional model. where each service or interaction with a provider is charged to the patient or insurance provider. In this model, incentive to choose the most appropriate and effective care (eg, diagnostic tests, treatment) may be missing; relying on the will and judgment of practitioners to hasten the individual to health and receiving a fee-for-service despite outcome. Fee-forservice may encourage multiple diagnostic tests and visits, as each visit and test yield income. Disease prevention/health promotion is typically not a focal point; rather a 'treat and street', or single care visit and the patient is on their way.

What is working in fee-for-service . . . and quick comparison to value-based payment

- If a higher level or volume of services is needed by the patient, the
 provider is paid incremently more to cover expenses. Patients with
 more risk factors or comorbidities receive the services needed. In a
 capitated or bundled payment model, the fee is 'flat', regardless of
 need or higher risk conditions.
- Providers get paid for providing a service. There is no financial penalty if there are situations or challenges for which they cannot control. Payor takes on the risk. In other 'flat fee' payment models (eg, capitation, episode-based), if there are complex patient situations, technology or process problems, the provider takes on the risk and higher costs incurred.
- Providers know the dollar amount they will be reimbursed for any given service, so the provider can assess the corresponding revenue. Taken across the spectrum of services, the provider can plan fiscally. In value-based payment models, such as a bundled or capitated payment structure, providers know what they will be reimbursed to treat a certain condition, or a group of individuals in a plan. However, treating that condition or group may be more involved, may cost more if there are unplanned comorbidities, complications, or even processes which do not maximize the value-based payment model.

What is not working in fee-for-service . . .

• Emphasis is providing the service and test ordering, without necessarily attention to appropriate or quality care, nor prevention.

- Reimbursement rates are often less than what it costs to provide services.
- Lack of payment for high-value services, such as patient education and follow-up.
- Inability to predict the cost to treat a condition, as emphasis remains on the immediate treatment/service (6).

Value-Based Payment Model – What It Is, the Upside and the Unintended Consequences

Value-based care is aligned with 'best practices', preferred care algorithms, often with an emphasis on combined services to manage or treat a condition. However, the pay-per-value model encourages healthcare institutions to provide care with such defined efficiency, that high volume chronic conditions may be neglected. To achieve value-oriented care, healthcare organizations have commonly pursued one of three models: 1) capitated, 2) bundled, or 3) value-based purchasing.

Three most common value-based payment models:

- → Bundled or 'Procedure- or Episode-Based' Payment provides a set fee for multiple services managing a single condition.
- → Capitated or Population-Based Payment fixed payment, over a period of time, based on members enrolled in the plan (regardless of care utilization).
- → Value-Based Purchasing payment model where clinicians and organizations establish processes and incentives to provide both quality and cost-conscious care. This may be a 'pay for performance' model, or a model where processes (care algorithms or indicators) are established. The healthcare organization and/or the physician may be paid an 'incentive' when predetermined quality and cost of care metrics are achieved (7).

Strengths of value-based reimbursement models:

- Encourages providers to assess care or decision-making algorithms, providing appropriate and quality care for given conditions or treatments (eg, joint replacement).
- Gives providers flexibility to determine the spectrum of services for any given condition, for the bundled or capitated rate (versus fee-forservice yielding one service/one payment).
- Bundled/procedure-based and capitation models have the potential to provide all stakeholders, including patients, with comparative cost data (across providers and geographic locations) (6).

Cherrypicking and lemondropping describe a controversial practice, fostered by value-based payment models when they do not account for managing complex patients.

Challenges and unintended consequences of value-based payment models:

- Quality or performance indicators are difficult to track and incorporate, due to the need for sophisticated analytics, the volume of data and demand for ongoing, continuous assessment (8).
- Clinical outcomes do not drive the reimbursement. The patient outcome could reflect inappropriate care, or a complication could occur outside the time period covered by the payment.
- Bundled/procedure- and population-based payments may not cover the cost of the care provided. The predetermined dollar figures are often derived from an 'average' and then discounted below that figure.
- For a population-based or capitated model, providers will get paid; regardless of giving care, appropriate or none at all.
- Procedure- and population-based models, in particular, do not account
 for managing higher risk individuals; those with comorbidities or severity
 of disease. This can be significant for providers serving populations
 with a higher prevalence and incidence of chronic conditions (eg,
 diabetes, obesity). When payment does not cover necessary care,
 providers can be motivated to 'cherry-pick' (healthier, compliant
 individual) and 'lemon-drop' (the high acuity, nonadherent patient).
- There may be costs incurred, beyond the provider's control, not covered by the bundled or capitation fee; such as where the care is received (6).
- The value-based purchasing model requires a complex commitment by the organization to develop the incentive program and process, as well as integrate physician professionalism (which implicitly acknowledges independent decision-making).
- Value-based purchasing may encourage practitioners to avoid patients who may lower their score; such as higher risk, complex patients (7).

Cherry-picking and lemon-dropping describe a controversial practice, fostered by value-based payment models when they do not account for managing complex patients. These individuals require more resources over extended periods of time, and have significantly higher risk for complications. When payment does not support the necessary care, it can promote the practice of 'cherry-picking' and 'lemon-dropping'. Cherry-picking involves selecting and treating individuals who are healthier, and whose care would be covered in the population- or episode-based reimbursement system. In contrast, lemon-dropping is the practice of dropping chronically ill, complex patients, whose care would likely exceed what the payment model would cover (9).

In a recent survey, about one-third of physicians would 'lemon-drop' patients with comorbid conditions or who do not follow treatment regimens. If a patient is potentially going to be a high user of resources, and those resources will not be reimbursed, then providers feel compelled to avoid the patient. The justification keeps the system intact with services available for others. Surgeons are familiar with this type of patient selection, due to the consideration of surgical outcomes and potential complications. The *American Medical Association's Code of Ethics, June 2016*, states that physicians have the right to select patients; excluding patients who could compromise their ability to treat other patients (9).

The Center for Healthcare Quality and Payment Reform identified a list of concerns with current payment models. First, because care for an episode may not be delivered by a single physician or facility, it's possible that accountability and cost are assigned erroneously. Secondly, the amount spent on care does not correlate with the appropriateness or quality of care. It is possible a less expensive and potentially inappropriate service could be chosen due to the payment model. Thirdly, risk adjustment methods are designed to predict spending and are based on historical data. Risk adjustment does not necessarily reflect patient needs, particularly unique characteristics such as functional impairment or multiple comorbidities. Finally, payment models may not adequately reflect differences in communities and geographical areas, urban versus rural, and socioeconomic factors, which all can impact the type, quality and availability of services. In these situations, providers can be penalized for factors outside of their control (10).

Value-Based Models in Action

Illuminating What 552 Leaders Identify as Results

In July of 2018, the *New England Journal of Medicine Catalyst Insights Council* set out to assess the 'marketplace' with respect to payment models (1). To what degree are healthcare institutions using the traditional feefor-service reimbursement model, or the newer value-based care model for payment, and what are the outcomes and barriers to value-based care thus far? The *Council* conducted a survey which yielded 552 respondents; about a third each executive, clinical leader and clinician, with representation from hospitals, health systems and physician organizations. Some of the key findings and interpretation of data are noted:

- Fee-for-service accounts for the majority of revenue at 75%; with 25% being value-based reimbursement, at their respective organizations.
- Almost half (46%) believe value-based models significantly improve care, and 42% indicate value-based contracts lower costs.
 At the same time, 36% of respondents are uncertain that value-based models will become the primary revenue source. This may suggest that more evidence is needed, as well as clarity regarding the functionality and meaning of value-based reimbursement.

- Barriers to implementing value models: 42% indicate infrastructure & IT requirements as the top barrier, followed by changing regulation/policy and administration as the next important barriers (34% and 33% respectively).
- Five metrics were rated as 'important' to 'extremely important' by 85% of respondents: outcomes, cost, safety indicators, patient indicators and process measures.

The NEJM Catalyst Insights Council summarized that most stakeholders believe healthcare costs are high and quality can be improved. Some are implementing value-based models. However, on average, 75% of revenue is still based on fee-for-service. Less than half of leaders and clinicians believe that value contracts can lower expenses and improve care. Several factors may be involved in the mixed review and utilization of value-based care. IT and the electronic health record (EHR) were identified as top barriers. The EHR is time-consuming and frustrating. Integrating patient/outcomes or indicators effectively within the system continues to be a complex challenge. The uncertain government and regulatory environment underscores the guarded position concerning if and how value-based care models will become the primary revenue model (36% of respondents).

Affordable Care Act's 'Hospital Readmissions Reduction Program'

The federal government, through the mandated *Affordable Care Act*, has positioned hospital readmissions as a measurement indicator for assessing the value of care provided. CMS began the *Hospital Readmissions Reduction Program (HRRP)* in October 2012. This program financially (via reimbursement) penalizes readmission within thirty days for certain diagnostic conditions.

As of October 2019, Medicare has decreased payment to over 2,500 hospitals (out of approximately 6,000 hospitals nationwide). This represents



penalties for hospitals, who readmit patients diagnosed with heart failure, heart attack, pneumonia, chronic lung disease, hip or knee replacement, or coronary artery bypass graft surgery. It appears to be inconclusive whether the *HRRP* has improved patient care and outcomes; as some studies have shown an increase in mortality, with reluctance to readmit. Other studies find readmissions declining,

without an increase in mortality (when adjusted for risk). It appears measuring the value of 'right care', by utilizing a 'no readmission' metric, may in itself be a misplaced value. *Kaiser Health News* reported that about 1,100 hospitals had a higher penalty than the previous year, and the same number had a lower penalty. The data from the *HRRP* appears inconclusive; that is whether monitoring readmissions is effective or meaningful (11).

Obesity – A Condition of High Prevalence & Risk, High Cost to Manage Payment Model Motivated 'Cherry-Picking and Lemon-Dropping'

A look at obesity may be apropos, as it is a condition of high prevalence and risk. Up to 70% or more Americans are overweight or obese. Obesity, along with the comorbidities, costs \$147 billion annually. Associated chronic diseases include heart disease, diabetes, stroke, metabolic syndrome and arthritis (12). When payment models are not adaptive,

particularly for obesity and diabetes, the practice of cherry-picking and lemon-dropping is cultivated. The studies below exemplify the situation and suggest steps that could be taken to address the nonalignment between payment model and complex disease management.

Body mass index (BMI) has long been noted to have inherent problems with assessing weight, and yet it remains instrumental for patient selection and treatment. A recent study evaluated the need to define



obesity by correlating metabolic risk factors. When these risk factors were taken into account, the BMI scale shifted based on ethnicity and gender. As healthcare organizations use the BMI as a criterion, it can lead to overdiagnosis or underdiagnosis of obesity as a comorbidity. For example, this can impact whether an individual is considered a candidate for surgery. Institutions may be using the BMI erroneously (or arbitrarily), and to ensure that patient selection for any given treatment will meet payment model goals (13).

Obese patients have a higher risk of infection and complications when undergoing spine or joint replacement surgery. Some bundled payment models, such as 'BPCI (Bundled Payments for Care Improvement) Advanced', are taking patient morbidity factors into consideration. Episode of care or bundled reimbursement may function best when there is collaboration among payor, specialist/physician

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and providers across the continuum of care. Then the providers can define the parameters of care (all potential services) and the associated costs upfront (14).

Renowned orthopedic surgeons debated the evidence for performing total hip or knee arthroplasty (THA, TKA) on patients determined to be obese. Deciding to treat these patients has implications for the patient and the institution. Large data analysis demonstrates higher complication rates when the BMI is greater than 40. Therefore, higher complication risk pushes institutions to establish a strict BMI cutoff for surgery. However, the case can be made that BMI is not a 'one-size-fits-all', that muscle mass and body build can affect the score. In addition, other factors are equally important, such as hemoglobin A1c, serum albumin and smoking status. Utilizing a strict BMI cutoff score to determine candidacy for THA or TKA may be impacting women and minorities the most, and denying care to those who could benefit if the BMI and other risk factors were assessed meaningfully and comprehensively. Finally, institutions can develop interventional strategies to help individuals address their risk factors prior to surgery (15).

Value-Based Models - Summary Highlights

Value-based care and payment models demonstrate effectiveness for some aspects of care delivery. Providers can establish how to care for certain conditions or episodes, defining processes and services. Part of value-oriented care requires identifying preferred care strategies for any given condition, and an associated fixed cost. With this value philosophy, standards of care have been evaluated and defined, with common goals of both 'cure'/treatment and cost-efficiency. In varying ways, this aspect of value-oriented care is exemplified in bundled and capitated payments.

However, unintended consequences for practitioners and patients are evident. Ensuring appropriate care and evaluating clinical outcomes do not drive population- or procedure-based models. Instead, they simply offer a bundle of services for a specific fee, or pay a flat amount per member, regardless of care/no care. Next, reimbursement may not cover the cost of care.

Importantly, one of the most challenging aspects of value-based payment is the lack of consistent accountability for higher risk patients; those with comorbidities and complex conditions. This can encourage the practice of cherry-picking and lemon-dropping. Furthermore, these higher risk patients are more common, as diabetes, obesity and other chronic disorders are rising in the United States. There are over 29 million people with diabetes, with about two million new cases annually. These value-based reimbursement models may not be designed to manage high risk patients, and at the high volume or demand chronic diseases require.

To operationalize value-based models, information technologies (IT) have flourished for administration, tracking, documentation and reporting purposes. The NEJM Catalyst Insights Council reported that almost half of clinical leaders and clinicians experienced IT and EHRs as barriers to care. In fact, whether value-based contracts improve care is evenly divided, from 'agree' to 'neutral' to 'disagree'. The same response is seen for lowering the cost of care. In the next section, we will note that consumer-patients experience similar overload and frustration with IT and EHRs; having a negative impact on patient-provider interaction.

A troubling unintended consequence of the CMS, *Hospital Readmissions Reduction Program* appears to be a lack of consistent, broad based achievement of the Program. Data does not support improved outcomes or decreased mortality. The results for hospitals incurring penalties yields no correlation; that is, on average, penalties do not decrease over time, as readmission rates fluctuate from year-to-year across hospitals. Facilities that received a higher penalty one year, may see improvement the following year; while just as many hospitals who incurred no penalty previously, may have a penalty in the next year. Furthermore, some hospitals may avoid readmitting those designated high risk patients, based on the *HRRP* incentive to not readmit. Instead, in a real value-oriented system, readmission would be based on patient need and appropriate care standards.

Six Principles of Value-Based Care (16)

- 1. Common sense predominates in organizations focused on value. Clinicians have the freedom to provide optimum care to each patient, which may be different than the organization's general practice or care pattern.
- **2.** Pre-established payment models (bundled payments and capitation) offer value-focused institutions freedom with less financial risk.
- **3.** Vision for patient outcomes is long term; such as preventing chronic conditions and delaying disease progression.
- **4.** Expanded roles of certain practitioners to achieve both value and efficiencies in care (eg, use physician extenders).
- **5.** Patient-centered decision making and culture of caring are valued.
- **6.** 'Whatever it takes' approach to providing care, focusing on patient outcomes with common sense solutions.

SECTION 2

PATIENT AND PRACTITIONER PERSPECTIVES
The *Movement is Life* FOCUS GROUPS - Real-Life Patient Feedback

The goal of healthcare is to achieve a state of health or best possible functional status, within our standard of care. The intent of payment models is to fund the needed services. Instead, we find payment models interfering with how healthcare is provided. Choices in care can be driven by the source and type of funds, instead of by appropriate care or what the patient needs. This is most evident in the management of chronic conditions.

Looking at patient and practitioner perspectives can enlighten how payment models are impacting the delivery of care, at a personal level for both of these stakeholders. To discover what people are experiencing when they seek healthcare services, *Movement is Life* conducted three Focus Groups in 2019. The goal was not to purposefully align with any payment model, or match 'experiences' with payment type; but instead select different geographic communities or service areas and ethnic groups, to ascertain consumer-patient perspectives, and look for commonalities and differences. Each group had between eight and twelve participants; all were female and over the age of forty. The Focus Groups revealed real-life challenges and frustrations during common, every day interactions with our healthcare system.

- The first group represented African Americans in Cleveland, Ohio, who receive care from the university hospital/health system or private clinic.
- 2) The next group consisted of **Hispanics in Chicago**, who obtain care from their community or private clinic.
- 3) The final group were Community Health Workers, of mixed ethnicity, in Hazard, Kentucky. They were both practitioner (public health, social worker, nurse), and patient (receiving health care where they work and live).

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Cleveland African American Focus Group

Participants in the Cleveland Group described situations where they were not informed regarding their diagnosis, test results, or treatment plans. Additionally, they had to repeat their conversation to multiple health care professionals during a single visit; thus giving the impression of no communication among staff. The Cleveland Group also experienced a lack of provider competence or attention to the patient's individual needs. For example, this included being asked to exercise despite having post-chemotherapy weakness, lack of attention and appropriate follow-through on prescription requirements and timeliness of recommended follow-up exams, and even on the verge of wrong site/side treatment. Finally, health care providers appeared to be discourteous, and demeaning through word and action, with perceived racial bias.



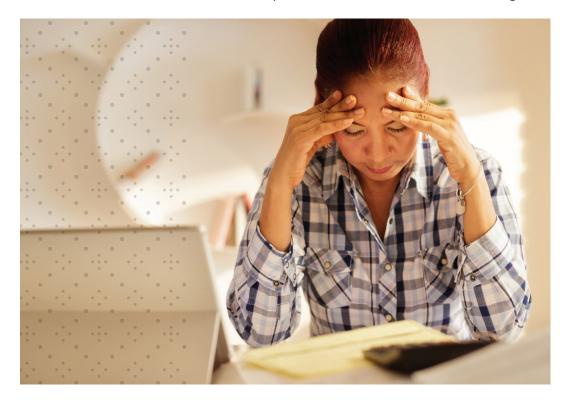
Diabetes and depression were conditions identified by the Cleveland African American Group, as being neglected by health care professionals. Participants specifically described the risk of diabetes was not being addressed (especially for youth), and the long term consequences of diabetes was not explained or emphasized. These participants felt depression is not recognized as a problem in the community, is therefore under-diagnosed, and not being given the same attention as physical conditions.

Table I – African American Focus Group Comments

Theme	Quotes from the African American Cleveland Focus Group
Lack of communication, impaired communication process	"The last time, this student, he was reading the information,he didn't hear a word I was saying." "I find it so irritating and frustrating to go to the hospital and have to explain the exact same thing to twelve different people. I think that is so ridiculous." "Why can't I just talk to [the physician or attending] in the first place, and let all of them listen to what I'm saying? That makes me more ill [repeating symptoms], because my blood pressure goes up when that [next] person comes in the room and asks the same questions." "Right, why can't they all be in the room? That happens at the clinics, too. So, why can't they all come in, listen to me, and then decide what they're going to do?"
Lack of competence, attention to patient needs	"When I went in to have my Medi-Port put in, cancer was on this side and he was trying to put it in on this [other] side." "With my family history, you want me to come back to your office in six months?" He said, "Yes. You should be more concerned about your grocery bill, than you are about this lump." [comment from a patient with positive diagnosis of breast cancer] "I was diagnosed with breast cancer and I had surgery and treatment. I went to see this new primary doctor I'm tired, and she's telling me to go workout and you won't be tired. Lady, I can barely go to work. I go to work and I come home, and I don't even make it to the bedroom. I make it to the couch." "The doctor never said, 'Because of your age, maybe you shouldn't be taking this medication anymore.' He didn't say that. None of them. The surgeon started it, and the primary care doctor continued to write that prescription." "I had lost weight, but because she didn't know what I had been doing, she never asked me, 'Are you working on losing weight?' She didn't say anything. She just jumped to, 'You need to lose some weight."
Lack of professionalism, courtesy, and perceived biased care	"I think that she probably would not have [treated] a Caucasian person that way, but I was just so angry because, first, of all, she didn't listen to me. She didn't care what I said. She was going to insist that I take this Fosamax." "I just thought they would treat my husband like that because he was black. So, I'm leery to leave him there [alone] to make sure that it didn't happen, because I saw a lot of things I really didn't appreciate."
Health care system challenges	"Some doctors, you have to wait three to six months before you can get in." "Now, they're giving you quotes upfront - what your estimate will be after the insurance has paid and they ask you for that money in advance." "It is really, bad. They're in a vice. They can't serve people like they went into the profession to serve." "'We do a pregnancy test on everybody who has abdominal pain' - which I didn't believe. I don't need a pregnancy test. I know what I've done or not done." "Insurance dictates they've got to see so many patients in an hour."
Common conditions not recognized or managed appropriately	"I don't think doctors know how to identify depression." "I never knew that diabetes was so bad, until I worked there. You see so many young people go to surgery to have toes, feet and legs amputated. I was just blown away. If they would have amputees go out in the community to talk to people about diabetes, people would listen." "I see students who are not controlling their blood sugar, and the families don't make sure that they're doing it."

Chicago Hispanic Focus Group

The Chicago Hispanic Focus Group also noted the flawed communication between patient and provider, and went further to address the electronic medical record. Clinical and non-clinical staff seem absorbed in the technology of the medical record, to the exclusion of patient interaction and dialogue. The electronic medical record process was identified as a barrier to communication, and in fact may steal time from authentic patient-provider discussion. Some participants felt the lack of attention and time on the patient was instrumental in their misdiagnosis.



This Group also noted a lack of professionalism and bias in the care received. Examples included inadequate care due to gang member association, doctor not wanting to touch the patient, rudeness, and perceived non-English speaking bias. Access to and scheduling a specialist was also described as a hurdle. As the Cleveland Group identified insurance as an outright frustration, so too did the Chicago Group. Insurance, what is covered, cost to the patient, and how to navigate both hospital/ clinic and insurance company processes are

sources of confusion. The comments from this Focus Group demonstrate the source of their frustrations (Table II).

Table II – Hispanic Chicago Focus Group Comments

Theme	Quotes from the Chicago Hispanic Focus Group
Lack of communication, impaired communication process	"I know that's the system, but they barely see you. They barely say hello, and they're already prescribing." "The doctors no longer even look at us, they're just at the computer. It's frustrating." "They are robots." "The technology, instead of helping, is hurting us. Because they no longer pay any attention to us, when they used to before." "Now they're distracted with the computer, sometimes even with the phone." "They give you a name, and over there they give you another name for the prescription. That's the generic, and you're just more confused." "I walked in, and I walked out. She didn't take time with me even to explain."
Lack of competence, attention to patient needs	"Some of the symptoms we feel, the doctor can't be sure of which disease, [so] he might give you a medication because they're similar." "Ma'am we'll need to reexamine it," he said, "because it's pre-cancerous." They didn't even want to touch it. They said, "Apply Vaseline. I'm going to give you this lotion." I got to my house really frustrated, and I burst my bump, and cured it myself." "Once I had a hemorrhage and the ambulance came My children arrived [at the hospital] and they asked if they were attending me already. They said, 'No, we are not running any studies, but probably she has cancer.' Like that 'She probably has cancer,' said one, 'or god knows what she has.'"
Lack of professionalism, courtesy, and perceived biased care	"My son was covered in blood, his head open. I heard the nurse when she said, "A gang member more, a gang member less."" "Oh, you know what, I can't give you an appointment, because I'll be in Cancun." I said, "Alright, but the tests, you can order those." "They give them [English speaking] better treatment, because they know they will complain, and we, even if we complain, we won't seek more help higher up. We just keep our problems." "Due to the language, we don't know where to go complain." "I do not know how to speak English. I go and ask for an early appointment, so I can leave early. I leave last of all — why? Because there are no people who speak [my language]." "No, the specialists that I've gone to do not speak Spanish, and I always leave confused."
Health care system challenges	"Lately, at the clinics, they no longer have doctors." "The clinic has very few doctors, they don't give us any time anymore" "Yes, that's the one thing you can count on, getting the bill." "I have a question. Why is it so expensive?" "We have this appointment, take it or leave it." If you don't take it, who knows how many months later" "The complaints, those mailboxes where one deposits the complaints, nothing ever changes." "Now, supposedly, they say that everything is confidential. It's not true, now with all this technology." "I still don't understand that process they have; where the government tells you that you have to have insurance and the administrators tell you what you can spend in the four parts." "That medical card, Medicare used to cover — now you need to take out another, and pay I don't know what." "Sometimes they don't even cure you. It's just the system to keep funneling money to the insurance companies from you by the system."



Kentucky Community Health Workers Focus Group

The Kentucky Community Health Workers represented a unique Focus Group, as these individuals were both healthcare practitioner and patients themselves. They shared common experiences and values with the African American and Hispanic Focus Groups, and in fact, reinforced recurring challenges and frustrations.

The Health Workers noted a lack of communication with patients across the spectrum of care. Providers are not discussing diagnosis, results of laboratory tests or treatment. As the Hispanic Group addressed the issue of too much attention on computers and the electronic health record, so did the Community Health Workers. Patients are not being given thoughtful attention, and discussion time with the patient competes with recording information.

Furthermore, quality of care appeared lacking, as multiple tests may be done and various doctors seen, yet a diagnosis or resolution did not occur. This Focus Group felt practitioners too often lacked knowledge and expertise, or at a minimum, the resulting care reflected a lack of competence. Additionally, providers were so focused on "appointment-based/single problem care", that even managing a previously diagnosed condition as part of the problem was missed. For example, a patient with diabetes was treated for the immediate issue, whereas a holistic approach to their condition of diabetes would have been appropriate. They described this as a lack of connectedness. Admittedly, appointment-based care is derived from the system itself, which encourages different appointments for each health problem. Thus practitioners tend to focus on only a single complaint or issue. This further leads to the lack of attention on prevention and education, especially for chronic diseases. A lack of timely access to care forces some patients to urgent care or emergency room, where they described the care in those locations as being frustrating and ineffective.

The recurrent theme of biased care was addressed by the Community Health Workers. They described care as too often judgmental. That is, patients are judged based on their weight, smoking, age and overall health status. Patients feel blamed and embarrassed. This Focus Group also described societal or community bias due to the high rate of opioid addiction in the geographical area. Providers are mistrustful of the pain identified by patients, and patients in turn are hesitant to address their pain for fear of being labeled an addict.

As the other two Focus Groups also identified, insurance creates significant challenges. Treatment or quality of care can be linked to type of insurance. If a higher copay is required by a specialist, then patients may not seek that specialist under their insurance plan. Medicare and Medicaid do not cover oral care, so that when an infection does occur in the mouth, it can lead to systemic or heart problems. If the nearest health system is for-profit, then costs there may be more expensive, regardless of insurance type.

Table III – Community Health Workers Focus Group Comments

Theme	"If you're obese [provider should ask], 'Do you realize you're overweight?' They don't come out and say that. My husband is overweight and diabetic, and he's never been told, 'You need to exercise.' Just take this [medication] and you'll be okay.' So, he can eat his cake and take the medication, and				
Lack of communication, Impaired communication process					
Lack of competence, attention to patient needs	"I had a situation two years ago, where I was going to the doctor [every week], and nobody could tell me what it was." "Well, they did numerous tests, and I kept saying, "I think it's my gallbladder." So, I went to a different specialist and the fourth one said, 'Let me do this test and, if it doesn't show anything, we will do a HIDA scan.' So, they do a HIDA scan, finally, and I went back in for the results and the nurse practitioner said, 'Oh, yeah, it's your gallbladder." "She's a diabetic. He won't recommend her for a diabetic eye exam. Nobody thinks about that. Nobody looks at the legs or anything." "He does not give her enough refills to [take] her until she comes back to see him." "How many surgeries do you have to have before you find out exactly what is wrong?" "They gave him allergy stuff. He needed an antibiotic [for ear infection]. A nurse practitioner at the same facility, gave him antibiotic and it cleared up." "Her doctor is taking care of her giving her diabetes pills and no diet [guidelines] or anything. She drinks Pepsi all day."				
Lack of professionalism, courtesy, and perceived biased care	"I was diagnosed with an aggressive breast cancer, and had to have a double mastectomy, and because of my age, they did not take me seriously." "They think you just want a pain pill. They don't think that you really have that pain." "I never mention it [pain], because I don't want to be one of those drug addicts." "He [the doctor] said, 'Have you ever been addicted to any pain medication?' he just automatically wrote me off as a drug addictIt was so degrading to me."				
Healthcare system challenges	"No, we can't see you. Go to urgent care." "Make sure you keep that appointment, but, if you get sick in-between, you're not going to be seen that day. So, more or less, you end up at urgent care [which] I call it scare care." "I asked, 'How many [patients] did you have today?' They had 84 patients with four providers." "They do whatever and never ask and never say anything, and then, you get this bill for all this stuff." "Like my mother-in-law, for instance, all the doctors, switching, going around trying to find somebody good. She is a diabetic. Well, how come you have never been referred to an endocrinologist that specializes in diabetes?" "Mine is a for-profit hospital in my county. The CT scan and MRI's are three times more than the next cities." "Just going to the ER with my insurance, it's a hundred bucks" "In our area, it is five hours waiting [emergency]."				

The revelations, however, do support the possibility that payment models and the demand to design and deliver costefficient and effective care ... are indeed impairing quality care, by rationing time and communication between patient & practitioner, focusing on prescribed algorithms of care and what will be reimbursed (or not), regardless of patient need.

Focus Group Findings

All three Focus Groups - unique in ethnicity, community and even facilitator - revealed common themes and experiences when receiving healthcare. Again, the purpose of the Focus Groups was not to propose a relationship between reimbursement model and quality of care. The revelations, however, do support the possibility that payment models and the demand to design and deliver cost-efficient and effective care. . . are indeed impairing quality care, by rationing time and communication between patient & practitioner, focusing on prescribed algorithms of care and what will be reimbursed (or not), regardless of patient need.

A lack of communication or impaired communication was one of the most significant concerns. Participants indicated they were not informed regarding tests, diagnosis, treatment plans or medications; and often noted the absence of straight-forward conversation with the practitioner. Interaction was instead misplaced on managing the electronic record. When conversation occurred, the practitioner appeared not to 'hear' or listen.

Another common experience was a **lack of competence in providing care**. This included not being attentive to the immediate and longer term, chronic needs (eg, not considering the current condition with respect to comorbidities or the whole patient presentation or history); not ordering diagnostic tests or the right tests; not providing 'connected' care (eg, not following through with medication history or pairing medication with diet/lifestyle modification). Some participants, across the groups, felt that certain conditions, such as diabetes and depression were neglected.

NATIONWIDE VALUES IN HEALTHCARE

The University of Utah Study

Survey respondents:

- > 5,000 patients,
- > 600 physicians,
- > 500 employers

Recently, a nationwide survey was conducted to determine the value characteristics of three key audiences: **patients**, **healthcare providers**, and **healthcare systems**. Each audience rated the components of value, which were defined as: 1) **guality**, 2) **service**, and 3) **cost**.

- → For patients, affordable <u>cost</u> was valued the highest. Aspects of '<u>quality</u>' followed in value importance. Quality included access to healthcare and convenience (times, location, and the total experience at appointments).
- → In comparison, the healthcare provider placed the highest values on <u>service</u>. Practitioners valued the <u>right tests</u> being ordered, and evidence of patient improvement or <u>return to health</u>.
- → Like the patient, the **healthcare system** valued **cost** as a top concern; including affordability and reimbursement/payment models.
- → Healthcare administrators/systems also placed a high value on <u>service</u>, seeking to provide care and treatment with <u>appropriate</u> <u>technology and competent practitioners</u>. (17)

All groups felt the weight and frustration of dealing with insurance and the out-of-pocket costs. There was a general sense, as well, that cost or type of insurance impacted the care received. Also, some encountered specific algorithms of test ordering or care; that despite the individual's unique presentation, the stepwise process had to be followed. No matter the payment model, it appeared the healthcare organization delivering the care was mechanical and dictated by insurance.

Despite the progressive transition to value-based care and value-based payment methods, the Focus Groups reveal an absence of humanism, quality and appropriate care. In the next section, Focus Groups discuss 'ideal' healthcare, providing additional insight.

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SECTION 3

IDEAL HEALTHCARE SYSTEM – Rehabilitating Relationships

Thus far, we have revealed a misalignment or disengagement among and between consumer-patients, practitioners, healthcare institutions and payors. Philosophically, agreement exists that quality, cost-effective care should be delivered across populations. Healthy people are not a burden in society or the system, and models that respect fiscal resources can provide prosperity. Looking at an 'ideal' healthcare system may bring these two goals together in a manner that we can work towards. Below are the Focus Groups feedback when asked about the aspects of a better or ideal system.



Cleveland Focus Group – Effective Communication, Partner in Care, Colorblind Care

The African American Focus Group identified clear, efficient (timely) and effective communication regarding diagnosis, lab/test results, and medication use as the most important attribute of an ideal health care system. They expect good communication during the patient visit, as well as prompt contact or call with test results. The next improved aspect would be timely care; both in being able to schedule an appointment, and when at the appointment, a short wait time. Care should be provided in an unbiased and courteous manner; from office staff to practitioner. Interactions should be fair and comfortable.

Personalized care, that is care that shows the practitioner is familiar with patient history is ideal. Equally important, people want to be a part of the decision making process, and want to look at natural or alternative methods of treatment. They seek a physician/practitioner who is both compassionate and a partner with them in attaining whole health.

Table IV - African American Focus Group Comments: Ideal Care

Theme	Quotes from the Cleveland Focus Group		
Communication	"I would expect for it to be explained to me whether they thought I knew it or not, then, ask if I understood what was said to me. If you are giving me a prescription, you would explain to me why you're giving me this medication If I had a test done, I would expect an answer in a couple of days." "If I call the doctor, I'd like for them to return my phone call."		
	, , ,		
	"Once you sign-in, they would call you within a normal time, and not have you sit forever."		
Timely care	"I don't want to wait three months before you can get an appointment. [At the office] of course, you're going to wait a few minutes, but [they] get you [seen] in a timely manner, five or ten minutes The doctor comes in shortly; not a half hour, 45 minutes later."		
	"I would just increase the patient/doctor time. When you're rushed, you forget some of the questions you have."		
	"With the perfect system, they're not mandated to see ten patients in an hour"		
	"I've got one word, a system that is colorblind - that would be my perfect system."		
	"If I'm going to the doctor and you're my kids' age, you don't call me [by my first name]. Don't call me Sweetie."		
Unbiased,	"The doctor's office staff would recognize me, and have a smile on their face."		
respectful, courteous care	"I had to learn to be an advocate for him because I just thought they would treat my husband like that because he was black."		
	"When you go see any doctor, if you do not want to have the residents in the room with you, you have a right to speak out against that. The doctors should ask you, "Do you mind having the residents in here?"		
	"[I want to] partner with my healthcare doctor who will work with me compassionately."		
Personalized	"I had to learn to be an advocate for him because I just thought they would treat my husband like that because he was black."		
care	"Sometimes people do need somebody else to advocate for them, because I was my mother's		
Shared decision making	advocate. My husband and I and my daughter, we were her advocate." "About going to the primary doctor, I would want someone to act like they recognize me, like it's		
Partner in care	not the first time they've ever seen me. Every time I walk in, feeling like I matter. A doctor would be familiar with my history and helping me walk through steps and all that needs to be done for whatever is going on at the time."		
	"I'd rather lose [weight] naturally than to be taking medications."		

"... a system that is colorblind - that would be my perfect system."

Chicago Focus Group – Personalized care, Dialogue, Shared Decision Making

Based on their experiences in the health care system, the Chicago Focus Group addressed the types of interactions and care they value. A top priority is personalized care; that is care where the doctor listens, and assesses the whole person, not just the current illness. The Hispanic Group values communication and dialogue with the provider, which promotes trust. Trust between provider and patient is more important than having a provider of the same ethnicity.

A "perfect health care system" would therefore provide equal and fair treatment to all patients. Practitioners would describe the situation or condition, diagnostic and treatment choices, and include the patient, so decision making is shared. Practitioners would demonstrate commitment to their profession, providing care that is relevant with patient-focus and understanding.

Table V - Chicago Hispanic Focus Group: Ideal Care

Theme	Quotes from the Chicago Focus Group			
Personalized, adequate care	"He was interested in what I needed. He didn't want me walking out of his office forgetting to ask a question. He was always attentive of my health." "For the doctor to consider everything, your problems, each symptom that you are feeling and in reality to be able to say, "Things are like this, let's try to do this," and if they give you medicine to say, "This is for this and this" "He'd make me take my shoes off and would examine my feet, the nails"			
Communication	"The most important thing for me, when I go visit a doctor, is having a good dialogue with my doctor. For him to understand me and for me to understand him. For us to have a good conversation. Otherwise, I won't achieve anything" "So, you can talk to them about your aches and your troubles." "To explain things." / "The doctor should be explaining."			
Professionalism: Ethically conscious, Equal treatment Commitment/Dedication	"For them to consider us human beings. Not like a number or as a money maker for the insurance companies." "For the doctors to be more conscientious of what they're doing." "They need to instill trust." "Not just because we don't know English, we should be treated badly. They've got to respect us." "For them to appreciate their profession and truly love that profession. And if they will love it, then they will know how to treat people with more respect."			
Cure focused treatment, Shared decision making	"To solve my problem." "Not let them choose because they shouldn't decide for us. They should let us decide as human beings." "I like him because he sent me to get tests immediately."			

"...having a good dialogue with my doctor.

For him to understand me, and for me
to understand him."

Kentucky Focus Group – Comprehensive Personalized Care, Awareness of Patient Incurred Costs

Community Health Workers described the sequential aspects of an ideal patient experience. The opening encounter with the front office staff should be prompt, professional and courteous. The practitioner should confirm the reason for the visit, and demonstrate familiarity with the patient's history. Providers should be focused on the patient, not on their phone or distracted. Care would be respectful and unbiased, with an absence of judgment regarding symptoms or lifestyle. Previous test results should be addressed and explained. Consideration for type of insurance and cost incurred by the patient should be evident, especially with regard to prescription medication. Care should be comprehensive and personalized, with attention to changes in medication based on test results. Finally, the patient could be referred to the community health worker, if the patient needs additional resources.

Table VI - Kentucky Community Health Workers Focus Group: Ideal Care

Theme	Quotes from the Kentucky Focus Group
Professional, unbiased, timely care	"[Provider asks]: 'How are you feeling? Why are you here today?' Then they listen." "If your blood pressure is high, [they ask], "Are you doing anything different?" "A short wait."
Comprehensive, Personalized care	"They should address the evident. [For example] if you are obese, they should tell you what you can do." "He follows up on bloodwork ordered at the last visit, and compares" "If they are a diabetic, how about, 'How long has it been since you've had an eye exam?' A diabetic should have one every year." "I notice you've lost weight, or your A1C went down" "Maybe we should change your medicine, because you've been on the same blood pressure pill and your blood pressure is still high." "They're also going to go over your diagnosis they will look at your overall health." "Let me send you to your community health worker"; [as we can be] vital to patients."
Insurance and cost awareness	"A huge thing is they are not aware of how much the medicine costs that they are prescribing. [They should be asking], 'Are you not taking your medicine because you can't afford it? Is there a generic I can call in instead of the name brand?'"

Are you not taking your medicine because you can't afford it? Is there a generic I can call in instead of the name brand?'

Providing quality, appropriate care within a system defined and confined by reimbursement, can place stakeholders at odds with providing 'health'.

Ideal Healthcare Findings

All Focus Group participants revealed identical, recurring themes. They characterized ideal healthcare as that which is patient-centered, with dialogue to ensure effective interaction, understanding, and shared decision making. Respectful, unbiased, nonjudgmental care was emphasized by all groups.

Regarding the impact of payment models, Focus Groups uniformly expect care that is not driven by insurance type or efficiencies which impact face-to-face time. Additionally, they want providers to be sensitive to their out-of-pocket costs for specialists and medications. For these three Focus Groups, portrayal of an ideal healthcare system was universal and consistent, across ethnicity and geographic community.

MONOGRAPH SUMMARY

Providing quality, appropriate care within a system defined and confined by reimbursement, can place stakeholders at odds with providing 'health'. Payment models, whether fee-for-service or value-based, have inherent weaknesses and strengths. Value-based, by nature, focuses on how to provide a standard of care for common, specific conditions or episodes, while streamlining costs. Population-based and pay-for-performance also encourage a similar approach to care.

Value-oriented models aim to improve both the quality and cost of care. However, in the process, patient-practitioner interaction and effective dialogue may be compromised. This can lead to a lack of patient-centeredness, which may hinder clinical outcomes. Furthermore, current payment models are not adequately flexible and adaptable to managing chronic and complex conditions.

As seen in the Focus Groups, consumer-patients and practitioners value communication, being informed, and inclusiveness in decision making. They value humanism, respect and nonjudgmental care. They expect that 'right' and competent care will be provided, regardless of insurance type and reimbursement model driven care algorithms.

In an ideal system, stakeholders are engaged to provide the best care within their community and accepted standards of practice. Payment models need to provide the cost-efficiency structure, without adversely impacting needed care. Stakeholders value quality care, and payment models that respect fiscal resources as well as allow appropriate care to be given.

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