The Role of a Patient-Centered Advisory Council in Defining Healthcare Quality

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Background

Background: The scientific literature on health care quality, health literacy, and chronic illness calls not for more data or innovative interventions but for a new paradigm that accounts for the importance of subjectivity and interpersonal relationships to these problems. Specifically, leaders in public health and health care quality are calling for a systems approach and for practice-based research to address the Quality Chasm.

Public Health Law and the Healthcare System are strongly influenced by roots in common law and Cartesian dualism; characteristics include:

>Adversarial rather than collaborative decision-making processes (competitive special interests)

>Decisions are made by an authoritative, "objective" third party (expert-centeredness)

>A centralized "body of (generalized) knowledge" is given force of law. (evidence-based care, best practices, standards, etc.)

Healthcare and Public Health decisions are made largely using hierarchical, expert-driven, evidence-based systems.

This approach is credited with many achievements r/t lifespan, infant mortality, disease prevention, etc.

But evidence suggests these systems are inadequate for addressing 21st century public health priorities bound to complex social determinants of health like:

Chronic Illness
Health Literacy
Quality Improvement

UAMS's Patient & Family Centered Care Initiative is a response to pressure from national agenda-setting institutions to be more "community-based" and "patient-centered."

Clinical departments are forming Advisory Councils with patients and families as members.

This is a critical analysis of the story of one of those councils.

Literature/Research Objective

Major issues in Patient-Centered Care Literature:

1) The overarching purpose is to improve quality

2) Patients must play a greater role in and take greater responsibility for decisions-making about their own health

3) Patient-Provider relationships must improve

4) Patient-centeredness is about organizational change, culture change, and system change.

Improving quality through patient-centeredness requires more than incremental changes ...it requires a paradigm shift.

Advisory Councils/Boards vary but councils with patients as members are an increasingly common component of patient-centered care and meant to address these issues.

Chronic Illness literature calls for quality improvement by increasing patients' influence on decision-making and improving the patient-provider relationship.

Health Literacy literature calls for quality improvement by increasing patients' ability to make health decisions by improving patient-provider communication.

In the literature, there are two fundamental facets of quality: static and dynamic.

Static Quality	Dynamic Quality
• Pre-defined standard • Numbers, categories	• Indefinable, Subjective • Intuition, feelings
• e.g. Performance standards • e.g. Health indicators	• e.g. I can't define it... but I know it when I see it
• Common in Healthcare	• Unique to each person

The quality and patient-centered care literature suggests that the overall quality of healthcare will improve when the patients' sense of dynamic quality, or subjectivity, is given more influence in health care.

IDENTIFIED NEED: Missing from all this literature is a practice-based and community-based public health perspective on the concept of quality where people are not conceptualized as patients but as members of a local community who are trying to do something about health.

Research Objective: The goal of this practice-based project was to demonstrate the application of a Model of Dynamic Quality to the process of advising members of an outpatient services clinic via a council comprised of patients and community members and to share its results and implications for public health practice and leadership.

Study Design/Data/Analysis

Data Sets and Sources: Participant observation was the primary means of data collection. Over the course of two years, the primary investigator and council participants digitally recorded the majority of the council and facilitator meetings and more than 50 semi-structured participant (key informant) interviews related to the council process. Other documents, artifacts, and more than 2000 field notes also comprise the ethnographic record that is the data set for this project.

Study Design: An intentional mix of ethnography and interpretive phenomenology were used to accommodate the ambiguous, situational, and dynamic nature of advisory council structures and the inherent importance of subjectivity to the concepts of health care quality and patient-centeredness.

Analysis: The data generated through this project were analyzed using two processes—first, guided reflection by the project participants, then critical interpretation of this data through the application of a theoretical Model of Dynamic Quality. Member checking (the process of returning to the participants, one or more times after the initial observation, in order to determine their thoughts on the accuracy or "truthfulness" of the information collected, the resultant themes, and conclusions) was used to address the need for rigor, validity, and "objectivity."

Setting: a Patient and Family-Centered Advisory Council for UAMS's Internal Medicine North Outpatient Clinic.

Participants: council members and any UAMS employees who had an influence on this process.

Data: actions, decisions, and comments of the participants.

Data Collection: participant observation, semi-structured interviews, reflective practice, and member-checking.

Ethnography: meant to capture the culture of a group.

Interpretive Phenomenology: to describe what it is like to be a part of that group.

This practice-based research was guided by three propositions for generating 'practice-based evidence':

1) the pursuit of knowledge should be acknowledged as a local and contingent process

2) research activity should be constitutive of difference,questioning the legitimation and repression of particular aspects of the world

3) theory-building should be seen as an adjunct to practical activity.

Compare the utility of this definition to the Association of Schools of Public Health's definition of Practice-Based Research: "systematic inquiry into the systems, methods, policies, and programmatic applications of public health practice."

A Model of Dynamic Quality

A Model of Dynamic Quality

Dynamic quality only happens in the interactive engagement of a unique, socially-situated individual with their unique, local environment represented here by the blue oval--the local context--where individual behaviors, social determinants, and environmental factors play out.

Since people's experience, values, and environment are always changing, dynamic quality is always subject to change.

Static Quality is created when two or more people have dialogue, drawing on their personal, subjective sense of dynamic quality to create objective tools (aka local knowledge) --e.g. words, numbers, definitions, rules-- used to collaborate in the local environment.

Static Quality (knowledge) can only change in dialogue. Changing the words and tools they use is a critical way that groups adapt to their changing environment.

Patient/Community Advisory Council Process

A system is designed "to control and produce standardized practices and outcomes."

People who work in a system specialize in certain aspects of reality or knowledge out of its local context and they're called subject matter experts, professionals, etc.

They use existing knowledge to construct objective tools (aka current professional knowledge) --e.g. terms, measures, theories, formulas models, rules, and "quality standards"--

These static quality standards are created by experts based on the pre-defined values and assumptions of their organizational culture without direct accesst to the local process of dynamic quality

This project is the study of how these two ways of creating knowledge come together in a patient-centered/community-based advisory council process.

Principal Findings

Principal Findings: Specific areas for improvement in local practice were identified and were organized around four themes that emerged from the data: Purpose, Decision-making, Organizational Structure, and Communication. Dialogue was needed about the purpose of the council and their ideas about quality. Transparency was needed in the decision-making process. The use of existing organizational structure to frame a patient-centered care model was a barrier to the development of new relationships and to the integration of silos. The concept of subjective/objective dualism and a bias for expert opinion were barriers to interpersonal communication in the process.

Regarding actions, decisions, and comments:

Do these move the decision-making process closer to the level of Dynamic Quality?

Do these create or constrain dialogue?

Theme 1
PURPOSE

There was a general consensus among all participants that the council process was to "make UAMS better." But we have to look at more specific data to understand what that means.

Explicit expectations that the council will move the decision-making process, closer to the level of dynamic quality and/or create dialogue:

Council facilitators were to advocate for council recommendations
Council members want to: "give more voice to patients"
Facilitators: creating the council is part of a movement
Council wanted to increase patient decision-making role
Council wanted to improve patient-provider relationship
Handbook: Council to increase patient decision-making
Handbook: Council to improve patient-provider relationship

Explicit expectations of the council that were defined by the institution:

UAMS directive: "Improve quality and safety"
Administrator: wanted Patient-Centered Medical Home status
Handbook: Expert-defined council member roles and goals

Explicit expectations that communication in the council would be constrained:

Administrator: "Council is not a place to air dirty laundry"
Administrator: "Don't want members who have an agenda"

Theme 2
DECISION-MAKING

Examples of decision-making process moving toward level of Dynamic Quality:
Council recommended clinic changes based on patient feedback
Council members defined the solutions
Council decided not to have formal group leader

It was hard to ascertain the influence of the council on clinic decisions:
Medical director took recommendations to admin. meetings
Employees said they were making recommended changes
Administrators said they didn't know about recommendations
Employees said changes were going to be made anyway
Council: "It's not clear what happens to the recommendations"
Power and decision-making hard for employees to talk about

Decisions about the council process that move toward Dyanmic Quality:
Council meetings informal; No formal by laws
Members involved in decisions about membership
Members were paid a stipend for attending
Some council members were community members at-large

Decisions made about the council that move away from Dynamic Quality:
Changes made with little council involvement
Administrators changed the name of the Council
Administrators changed meeting location
Administrators changed membership criteria
Administrators changed Council facilitators
Administrators ended stipends

Theme 3
ORGANIZATIONAL STRUCTURE

The Council's place in the organizational structure can be defined to some extent by who attends its meetings.

Examples of how the Council defined its place in the organizational structure:
Council invited some employees to the meetings
Chancellor's initiative created a new line of authority
Council facilitators from Clinic Administration and from other colleges
Council members were patients and community members

Examples of how the Council wass defined by the institution:
Some employees were appointed to the council
Appointed employees had pre-defined roles/authority
New membership requirements defined by administrators
Community members were phased off the council

Throughout the changes to the Council's connection to UAMS, participants maintained there were two important factors about the employee who connected them to UAMS:

1) The nature of their interpersonal relationships with council members and with other employees; and

2) The degree to which they were "into it"; i.e. their personal definition of and enthusiasm for "patient-centeredness" and their stake in the status quo.

Theme 4
COMMUNICATION

Examples of how dialogue in council process was created:

Employees, patients, and community members were together in a room
Relationship-building was important to council members
Council members socialized before meetings
There were some interpersonal interactions outside meetings

Examples of how dialogue in the council process was constrained:

Participants : subjectivity get in the way of facts
Participants: goal of council communication was to get facts
Employees: "It's all about the data." "We must have data."
Employees: "If we cannot show real data to doctors and administrators, nothing will change."
Administrators: Patients excluded if "too outspoken" "had agenda"
Employees were to avoid unscripted emotions
Employees were to "keep a united front"
Employees were not to "air dirty laundry"

Conclusions

Conclusions: The practice of patient-centered care is difficult in an expert-driven culture. Evidence-based templates, expert advice, and financial incentives offered by traditional, authoritative agenda-setting institutions in health care and government are of limited value in local practice. The concept of Dynamic Quality and the principles of practice-based research can help identify and address problems encountered on the local level when trying to move the culture of hierarchical, expert-centered health care organizations toward patient-centeredness.

PURPOSE: Improving quality meant system change to some participants and national recognition to others. Patient-centered care was more often characterized as an objective of the organization rather than a new way of doing things. This calls for dialogue between people and their providers.

DECISION-MAKING: The council's role in decision-making was not well-defined. Council members did not know what happened to recommendations they made or how they influenced decisions. They were minimally involved in defining parameters of the group. This calls for dialogue and transparency.

ORGANIZATIONAL STRUCTURE: The council was an opportunity to create new relationships across disciplines but there was a tendency to stick to existing organizational structure which relegates community members as outsiders and effectively places patients at the bottom of the hierarchy.

COMMUNICATION: If employees are set on collecting data, then emotions and subjectivity will seem like noise rather than an opportunity for developing relationships. Effective employees develop efficient ways to reduce noise so they can collect the data they are incentivized to collect. Data collection, as a goal of communication, also clouds the fact that employees are people, too, who have personal and emotional stories to share in dialogue with patients.

Patient-centered care is hard to do in a hierarchical, expert-centered organization.

The application of a Model of Dynamic Quality and practice-based principles to a process intended to be patient-centered or community-based can help identify specific areas within the process, organization or system where...

1) dialogue is needed about purpose and about the definition of quality

2) decision-making is not transparent

3) existing organizational structure prevents new relationships and integration of silos

4) barriers to communication exist

Balance as a Metaphor

Prominent theorists in organizational communication and in public health, use balance as a metaphor to describe the relationship between systems and individual people in communities.

Trethewey says the creativity of individuals and the constraints of an organizational culture are balanced through communication between individuals and organizations.

Gostin says Public Health is achieved by balancing individual freedom with a system of public health law.

Balance as a Metaphor

In Patient-centered Care literature, this is the partnership model...where the expert and the patient bring their respective knowledge together as equals.

These influential scientists are saying that systems are essential because they balance out the dynamic aspects of humanity.

The Model of Dynamic Quality used in this project is subtly, but importantly, different than these.

Assumptions of the Model of Dynamic Quality

In this Model of Dynamic Quality, there is tension between these two approaches to knowledge and using the power of one takes power from the other.

BUT, instead of characterizing this as a process of finding a healthy balance between two essential components, this model assumes freely associating people in communities are essential and that no particular system, tool, law, professional knowledge or standard of quality is essential to public health.

Major Assumptions of this Model of Dynamic Quality

Public health improves when people in communities do most health-related work.

Public health declines as health system power increases.

Implications for Practice and Policy

Implications for Public Health Practice and Policy: In order to address the 21st century health care challenges of quality improvement, chronic illness, and health literacy, current leaders and policy makers must acknowledge the limits of expert-defined "quality standards" and explore ways to give the power and responsibility for defining health and health care quality back to the public. Systems science, practice-based research, and a Model of Dynamic Quality, as demonstrated here, are useful tools toward that end.

IMPLICATIONS FOR PUBLIC HEALTH PRACTICE, POLICY, AND LEADERSHIP

Quality can be a more useful concept when defined not as conformity to a standard, but as an ongoing process of adapting to a local environment.

Public Health can be a more useful concept when defined not as a goal or objective, but as a potentially helpful perspective on local activities and problems.

Health Literacy can be a more useful concept when defined not as an individual trait, but as a local community's capacity to define and meet their own health standards.

Ask "Why?" Why are we studying, promoting, or using patient-centered care models? To meet expert-defined standards or goals? To capture financial incentives? Or because these are the kinds of tools needed to strengthen communities?

The application of a Model of Dynamic Quality can help identify specific areas where power and responsibilty are not being moved toward people in communities.

Recommendations for Creating Advisory Councils

Start with relationship building.
Create opportunities for informal interactions between patients and staff in the community and on campus.
Acknowledge the importance of being physically present.

Allow Councils to be as self-defined as possible.
Begin meetings with dialogue about why people have come to the meeting and what they expect to achieve.
No formal presentations from employees unless they are called for by the council in the course of their dialogue about the purpose of the group.

Councils should control their connection to the organization.
Connections should be built on interpersonal relationships
Connections should be flexible and mobile up and down the existing chain of command.

Decision-making shoud be a major focus of the group.
Deciders should address the council in person about the rationale for a decision and why that person believed it was their responsibility to make the decision.
The council should decide when an issue is resolved.
Employees should always ask, "can this decision be made by the council instead of the organization?"

Facilitators and council members should ask "Why?" a lot.
Question all procedures and agenda items for, "how does this activity/item create or constrain dialogue?"