Article

Health Care User Perspectives on Constructing, Contextualizing, and Co-Producing "Quality of Care"

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Abstract

Most of the research on health care user "quality of care" perspectives seeks discrete and measurable indicators to advance quality improvement (QI) goals. This lacks sufficiently grounded query about the meaning of "quality of care" for health users, and how context influences their ideas and experiences. We studied this between 2010 and 2011, repeatedly interviewing and shadowing 45 individuals in three of New York's hospital-based outpatient HIV care settings during routine visits. We found participants using common terminology, but across the cohort meaning varied and employed personal narratives. Participants conveyed the impact of historic and current experiences of stigma and discrimination on limiting access to care, and showed its destabilizing effects on quality constructs. Participants also felt they contributed to their health care settings' delivery of quality care. From our findings, we discuss the applicability and implications of "co-production" to conceptualize health care as jointly delivered by typical "givers" and "receivers" of care.

Keywords

Defining, measuring, and improving the quality of American health care have been challenging but persistent goals for several decades (Honore et al., 2011). In 2000, the Institute of Medicine's (IOM) *Crossing the Quality Chasm* advanced as the six areas of improvement: safety, effectiveness, timeliness, equity, efficiency, and patient-centeredness. It defined the patient-centered principle as care that is "respectful of, and responsive to, individual patient preferences, needs, and values" to "guide all clinical decisions" and redesign health care systems (IOM, 2001a, 2001b). This endorsement, along with others of its kind, was celebrated for elevating the patient-centered care norm and, in turn, expanding the role of health care users in defining key constructs of health care quality (Boaden, Harvey, Moxham, & Proudlove, 2008; Conway et al., 2006; R. Epstein & Street, 2011; Groene, 2011).

Numerous studies followed to examine user ideas about "quality of care" under the headings of patient "perception," "satisfaction," and "experience" research (Sofaer & Firminger, 2005). From this literature, features that users considered as "quality" can be collated and thematically grouped as follows: the "interpersonal," which expresses the value health care users place on patience, respect, empathy, comfort, communication, and acknowledgment; the "organizational," focusing on wait times and the coordination of services; "environmental" elements pertaining to the physical comfort in care; "structural" concerns around issues of access; and "technical" priorities to describe medical procedures, tests, and treatment outcomes (Deledda, Moretti, Rimondini, & Zimmerman, 2013; Greenhalgh & Heath, 2010; Jha, Orav, Zheng, & Epstein, 2008; O'Connor, Trinh, & Shewchuk, 2000; Rao, Clarke, Sanderson, & Hammersley, 2006; Sheraghi-Sohi et al., 2008; Sitzia & Wood, 1997; Stange, 2008). The literature also demonstrates researchers' interests in understanding how various "context factors," like demographic characteristics and expected/prior health care experiences, influence users' preferred features (Oermann & Templin, 2000; Sofaer & Firminger, 2005). Research has also been undertaken to appraise the relative priority users give to one quality construct versus another, as in one study where users were asked to compare seeing a favored provider with enduring a longer wait time (Rao et al., 2006).

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This research informs a number of user-based satisfaction survey instruments, intended to enable the monitoring and improvement of health care performance (Holzer & Minder, 2011). Studies have confirmed associations by reporting that higher ratings (indicating greater satisfaction) positively correlate with certain health outcomes (see Greenhalgh & Heath, 2010; Rozenblum et al., 2011). Such findings have also lent support for several allied initiatives directed at improving services via stronger patient-provider shared decision-making (Conway et al., 2006; Deledda et al., 2013; Rao et al., 2006; Rozenblum et al., 2011), increasing users' technical biomedical knowledge about self-management competencies (Bodenheimer, Lorig, Holman, & Grumbach, 2002; K. Epstein, Laine, Farber, Neson, & Davidoff, 1996; Fries, Lorig, & Holman, 2003; Greenhalgh, 2009), and enlarging their consultation role in improving care delivery (Beresford, 2012; Luxford, Safran, & Delbanco, 2011; Thompson, 2007).

Problematizing the User-Based Quality of Care Literature

A review of the quality of care literature indicates that it prioritizes reliable, discrete, and measurable units, which through standardization can be confidently leveraged (as in, increased with a set of identified mechanisms) across health care users (Lin & Dudley, 2009). Curiously, the aim is so taken for granted that researchers who note the instability of user constructs based on being difficult to define and measure call for better designs to surmount the problem and improve the metrics (Stange, 2008). Whether the emphasis is placed on studying quality variability in complex systems of care (R. Epstein, 2009), investigating how "context" factors shape perceptions (Sofaer & Firminger, 2005), or refining relational vocabulary (Deledda et al., 2013), ultimately the literature is saturated with calls for better standards in the form of "a more precise vocabulary . . . to achieve quality and translate it to other settings" (R. Epstein, 2009, p. 456).

Social scientists examining the production of scientific knowledge have shown how biomedical and health care research agendas can be probed for particular beliefs and values, and how they inform (and limit) what and how information is collected, interpreted, packaged for dissemination, and implemented into practice (Aronowitz, 2008). They have found that attention to the social processes shaping the production of knowledge through research is often obscured once analytic formulations and accompanying activities become secured as "common sense" (S. Epstein, 2007). Indeed, the overwhelming agreement in metricizing user-centered quality of care norms appears to have achieved this normative status.

The IOM as point of departure appositely points to the forceful mark of the Quality Improvement (QI) framework

on the research produced about user-based quality of care ideas. QI is a quantitative, data-driven approach to improving health care by using "accurate and powerful measurements" to define which elements need to be changed, and whether their implementation result in measurable improvements (Batalden & Davidoff, 2007). QI does not necessarily dictate what the metrics should be, but rather formats all information into "equivalent" (Lakoff, 2005) content, which can be mobilized through defined improvement processes. In the case of adapting user perspectives on quality of care into a QI framework, equivalency works by finding features consonant with preexisting principles (as articulated in technical, organizational, and environmental groupings). It also identifies "other" user-based values, such as all those interpersonal features, which stand outside of preexisting values while retain their ability to conform to QI mechanisms of improvement (as evidenced by the "shared-decision making metric").

Some researchers praise the incorporation of health user perspectives into QI because it helps them gain entry into a system that has been skeptical of their capacities to participate (R. Epstein & Street, 2011). Greenhalgh and Heath (2010) suggest that enabling user input in the mainstream (albeit measurement-driven) health care improvement world significantly lessens critics' abilities to "denigrate and ignore" (p. 6) users. While we are sympathetic to the need for securing a seat at the table, there are notable drawbacks when transferring user perspectives into an already-codified QI framework, which we think are important to point out, and to which we believe our study was able to respond.

The first and most obvious is that the existing approach may significantly obscure user ideas and values that are not equivalent, and so are unworkable within a QI framework. For example, it would be difficult to imagine a QI project to improve a provider's demonstrated "liking" of a user, even though users have articulated that they want to feel this from their providers (Greenhalgh & Heath, 2010). A second problem arises from QI's focus on producing units of measure, which has led to what John Bate characterizes as factors-based modeling (Bate, 2014). As a factors-based modeling tactic, QI-mediated quality of care research not only privileges the measurability of quality features but it also extends to contextual—or factors-based—determinants. Through this logic, context factors can only enable, or constrain the value of a construct, or its relative importance. For example, a factor-based formulation might identify an individual's level of education as influencing the relative importance of a particular feature of quality. However, this approach misses out on many key questions, like: Does education level lead to the formation of particular quality constructs? If a notion of quality comes to exist, how might education dynamically shape how that particular social construct is

not only defined, but rendered meaningful through the process of health seeking by the health care user? Exploring such questions deepens our understanding of user engagement with notions of quality.

An Alternative Approach to Study User Quality of Care Constructs and Contexts

We conceived of the Consumer Lens Study (CL) of the New York State Department of Health AIDS Institute as contributing to a patient-centered approach to quality of care research without reproducing the approach taken in much of the literature. Rather, the study aimed to explore HIV positive health users' ideas about quality of care, as well as how and why such ideas are meaningful. We used a grounded approach to define constructs, and consider the myriad ways contextual influences shape users' perspectives. We let participants tell us what was meaningful about quality. We were open to its dynamic aspects and so explored ideas within and about routine health care delivery settings.

Despite our critique of the literature, it is a rigorously collected and analyzed body of work derived through a particularly widespread logical framework. Furthermore, the problems we have laid out do not necessarily negate its potentially robust explanatory power. We have been mindful not to let QI encumber data collection and analysis, while aiming to set our study in conversation with existing quality of care research. For these combined reasons, we were guided by setting up a "framework analysis" to investigate the "fit" between the literature and our study (Dixon-Woods, 2011; Gale, Heath, Cameron, Rashid, & Redwood, 2013). We treated the existing quality of care literature (as we have defined it in this article) as one case, and CL findings as another. We then established two areas of thematic comparison. The first explored "quality of care" as defined by health users, asking whether our study generated the standardized notions of quality found in the literature. This led us to design questions and conduct our analysis in a way that was open but not limited to finding recurring variable domains. We incorporated some content analysis measurement techniques to query the existence of standardized ideas of quality.

Our second comparative theme pertained to the topic of context. We once again focused our concerns by comparing the conceptualization of context in the literature with our study. Here, we were open to our data securing, surpassing or redirecting us from a factors-based approach. We were prepared to consider a more dynamic relation between notions of quality of care, and the forces shaping them.

Method

Setting

We recruited HIV positive individuals receiving care at one of three hospital-based, comprehensive multidisciplinary care and service delivery programs in New York State, which are long-standing programs dedicated to caring for people with HIV/AIDS. A dedicated team of clinicians, case managers, and support staff provide primary and specialty care and select support services. There are currently 39 such sites across New York, treating nearly 40,000 individuals. The three sites involved in this study represent urban hubs, two in New York City and one in the upstate region. Each program receives some grant funding and accepts public insurance (Medicaid/Medicare) as payment for services.

Participants and Research Procedures

We sought 45 participants, distributed evenly across the three clinics. Participants had to be HIV positive, at least 18 years of age, and have attended the clinic for at least 12 months. To realistically reflect the HIV positive population in New York, histories of drug use or mental illness did not warrant exclusion. An accurate distribution of participants based on race, gender, and length of time in care was achieved. Recruitment initially consisted of approaching every fifth individual who came into the clinic for routine scheduled appointments. Then, when 10 individuals were successfully recruited, a phased-in ad hoc quota procedure was adopted to fill in gaps in representation while retaining random selection.

Each participant went through a two-step consent process prior to participation in accordance with the study protocol approved by the New York State Department of Health Institutional Review Board (#09-038, authorized on May 17, 2010), and the three participating hospital institutional review boards. Procedure entailed a member of the clinical staff initially approaching potential participants to provide a brief introduction about the study. Those interested met with a member of the research team who described the study in detail and, where appropriate, continued with a thorough consent process. Health user and hospital names have been anonymized in this article to protect all participants' identities.

We used an open-ended, qualitative, grounded theory mode of investigation (Charmaz, 2014) over 15 months using in-depth, in-person interviews with enrolled participants. Each participant was interviewed by A.B.L. (primary interviewer) or M.S. on a repeated basis, the target being four meetings over 12 months to conform to quarterly visit schedules. In addition to interviews, A.B.L., M.S., or D.T. accompanied participants through

the public spaces of the clinic, such as the waiting room, registration and check-out stations, and hallways, recording interactions and documenting flow. Interviews were generally conducted at the appointment's conclusion.

Consistent with an inductive approach, each of the four anticipated interviews used open-ended questions (such as, "What does 'quality care' mean to you?") and invited participants to direct the discussion through their responses. Interview one focused on defining "quality of care"; two pertained to quality and overall health; three focused on the health care organization and perceptions of how it worked; and four asked follow-up and clarification questions. Interviews were audio-recorded with permission. They took place in private rooms at the clinics, while the final interview occurred at a place of the participant's choosing. Participants set the length of the conversation, ranging from a few minutes to over an hour. Participants received a US$5 food card at the completion of each interview as a token of appreciation for their time.

Analysis

Analysis occurred in two phases. During data collection, interviews were immediately transcribed, read, and flagged up with questions that could be probed during future meetings. Early topic lists comprised concerns researchers knew would be relevant pertaining to the framework analysis technique (e.g., definitions of quality of care, factors shaping quality constructs, experiences in health care settings), as well as emergent terms and concepts researchers found to be repeating across the interviews (e.g., kinship terms, discrimination).

The second phase began at the conclusion of data collection. Remaining interview transcriptions and other documentation (fieldnotes and visit flow sheets) were coded and used to refine the topic lists. All interview transcripts were read several times, and topics were rechecked by A.B.L. M.S. participated in coding and discussed category fit. A.B.L. and M.S. extensively discussed findings with the other researchers (B.A. and D.T.), and with an interdisciplinary advisory group of HIV/AIDS experts to generate higher order themes. A.B.L. moved back and forth between the terms, themes, and the transcripts and fieldnotes to deepen an understanding of participants' expressed meaning. Emerging insights were again evaluated against the literature to assess the unique contribution offered by this study.

Results

Data were collected from May 1, 2010, through September 30, 2011. Fifteen participants were successfully recruited at each of the three DACs (*n* = 45). Table 1 gives some of the 45 participants' demographic characteristics, mirroring each clinic's race and gender census.

Table 1. Participant Characteristics.

	Participating Clinic		
	1	2	3
Total participants[a]	15	15	15
Average age	51	51	50
Gender			
Men	7	9	6
Women	8	6	9
Race			
White	0	8	1
African American	9	4	10
Latino/a[b]	6	1	2
Other[c]	0	2	2
Year of HIV diagnosis (average)	1996	1998	1997
First year at clinic (average)	2003	2003	2001
Receiving public insurance (%)	100	93[d]	100

[a]Self-reported information, except for first year at clinic.
[b]Latino/a: Jamaican, Guyanese, Puerto Rican, or Caribbean.
[c]Other: Native American, African, or mixed race.
[d]Denominator = 14.

The average age of the participants across the three clinics was around 50 years, conforming to the "greying" of the U.S. HIV-infected population (National Institutes of Health, National Institute on Aging, 2009). Most participants at each of the sites were unemployed, and qualified for public entitlements for medical and other living expenses. Most of the participants accessed a range of additional services including case management, support groups, home health assistance, housing, and transportation.

Results in this section focus on data generated from participant interviews, which produced 12 topic lists across three themes. The next sections provide results around the thematic areas of *Pattern-Free Quality Terms, Significant Context Factor*, and *Participating in "Quality Care."*

Pattern-Free Quality Terms

Table 2 presents a comprehensive list of the 58 terms used 214 times by participants to describe "quality of care." Terms represent a composite category constructed by researchers combining terms of the same sentiment, or they are direct concepts articulated by one or more participants. It is notable that 90% of the terms conveyed interpersonal features consistent with the quality of care literature. Within this grouping, "care" was the most commonly used term, registering 10 times. As Table 3 shows, quality of care features also fit into technical (e.g., "thorough"), environmental (e.g., "comfortable"), organizational (e.g., "coordinated") and structural (e.g., well-located) groups found in the literature. Each of the five quality groupings was represented among the most

Table 2. Term Use by Participants to Describe "Quality of Care."

Participating Clinics		
I	2	3
68 Terms[a]	83 Terms[a]	63 Terms[a]
Nurture, informative, Integrated, compassion, thorough, concern, safety, comfort, loves, provides resources, shared-experience, well-located, attuned, care, coordination, trusted, treatment success, supportive, respectful, demeanor (friendly/smiles/kind/nice/personable/pleasant), family-like, gloveless, beyond scope, inquisitive, sharing, courteous, familiar, available, flexible, understanding/accepting, knows me, responsive, listens, patient, praising, at ease/welcoming, interesting	Conversant, thorough, care, comprehensive, attuned, equality/dignity, knows me, at ease, cutting edge, calls, supportive, provider key, compassion, listens, responsive, demeanor (friendly/smiles/kind/nice/personable/pleasant), comfort, jokes, shared-experience, shared decision-making, trusted, well-located, close relationships, safety, knows me, inquisitive, responsive, respectful, understanding/accepting, equality/dignity, belonging, problem-solver, well-located, watch over, informative, at ease/welcoming, beyond scope, de-stigmatize, gives confidence, responsive, knowledgeable, decision-making involvement, coordination, professional, financial awareness, concern, flexible, supportive	Comprehensive, treatment, responsive, care, jokes, demeanor (friendly/smiles/kind/nice/personable/pleasant), flexible, gives hope, listens, treatment success, conversant, self-care, informative, family-like, available, calls, truthful, watch over, shared decision-making, responsive, loves, understanding/accepting, respectful, thorough, decision-making involvement, attuned, comfort, beyond scope, concern, compassion, knows me, coordination, specialized

[a]Unique terms listed.

common 13 (22%) terms across participants, accounting for approximately half of all terms.

Beyond being able to cross-reference terms by quality types, we could not identify consistent meaning for any particular term. Across participants, familiar "quality of care" vocabulary was used in nonstandardized ways. Table 3 illustrates this finding by listing the most common terms along with the multiple associated definitions. For example, a term like being "known" was defined by one participant as a provider being familiar with a participant's name, and by another participant as being recognized as a "whole person." Furthermore, the third column shows the range of definitions for the same terms, cross-referenced by groupings from the literature. "Comprehensive care" fit into the interpersonal domain, when a participant used the term to describe the provider attending to her entire person "including mind/soul," to the organizational when another participant described service coordination, to the technical when a third participant used it to talk about her medical needs. Similarly, "comfort" described both a physical, and an environmental state for two different participants. "Responsiveness" indexed technical and interpersonal ideals. Sometimes, one term encompassed two or more domains in the same definition.

In addition, terms central to the quality of care literature overall were invoked with altogether different meaning by the participants. The IOM principle of "safety" illustrates this point. The term is defined by the IOM as avoiding injuries to patients by selecting the correct biomedical procedure and executing it in a coordinated manner, and has been identified as a critical area of intervention for health care. One man using the term repeatedly said,

Years ago it was bad . . . I would walk a half a block and I would feel like I had to rush back in to *feel safe* and normal, not able to do things. . . . After I was diagnosed [my provider] came to see me and I was in bad shape . . . [with him] I *felt* very comfortable, very *safe*, so I been coming . . . I think it's just his whole demeanor. . . . I felt very *safe* and, like, I was going to be OK. When he explained to me that I could be, that there's help for me, I remember feeling *safe*. His voice, he looked in my eyes and I felt *safe* when I spoke to him . . . Yeah, I feel. My word is that I feel *safe*. That's the only word I can think of. (Clinic 1)

For this participant, safety was an important term, which had a different meaning than "avoiding injury," serving as a positive expression of feeling about a provider. It was determined not through assessing technical capacities, as is the basis for safety assessments in QI, but through what he felt was conveyed by the provider's body language. Another participant who also used the term *safe* to describe care described it as a feeling of "dignity," "respect," and "a sense of worth . . . not [being] looked down upon" (Clinic 1). While participants may have recognized and possibly agreed with the importance of IOM's more technical definition, it is noteworthy that their vernacular privileged a different and possibly contrary set of meanings compared to standing uses within health care's QI field.

Significant Context Factor

During the interviews, participants described key features of quality of care, and their experiences receiving health care that expressed such features. Stigma and discrimination was a dominant force participants brought

Table 3. Most Common Terms, Use, and Fit With Quality of Care Literature by Type.

Term	Use	By Type[a]
Care (10 uses)	1. Takes an interest in (5 uses)	1–2. Interpersonal
	2. Genuineness (5 uses)	
Informative (10)	1. Teaches self-love (1)	1. Interpersonal
	2. Provider gives information (5)	2–6. Interpersonal/technical
	3. Keeps body "in tune" (1)	
	4. Exchange of ideas (1)	
	5. Giving providers information (1)	
	6. Taking information (1)	
Demeanor (10)	1. Personable (1)	1–6. Interpersonal
	2. Friendly (2)	
	3. Kind (2)	
	4. Nice (2)	
	5. Pleasant (2)	
	6. Warm (1)	
Thorough (8)	1. Goes over/checks everything (8)	1. Technical
Comfort (8)	1. Of feeling (4)	1. Interpersonal
	2. Clinical space (4)	2. Interpersonal/environmental
Respectful (8)	1. Being/doing (4)	1. Interpersonal
	2. Maintains confidentiality/privacy (4)	2. Interpersonal/technical
Comprehensive (7)	1. All needs (3)	1. Technical
	2. Including "soul/mind" (2)	2. Interpersonal/technical
	3. All services (2)	3. Organizational
Listens (7)	1. Doing (5)	1–3. Interpersonal
	2. Genuineness (1)	
	3. Leads to talking (1)	
Responsive (7)	1. Changes TV when I ask (1)	1. Interpersonal/environmental
	2. Takes seriously (2)	2. Interpersonal
	3. Medical needs (2)	3. Technical
	4. Medical and other needs (1)	4. Interpersonal/technical
	5. Comes to me (1)	5. Interpersonal
Compassion (6)	1. Being/doing (6)	Interpersonal
Beyond Scope (6)	1. More than doctor role (2)	1–2. Interpersonal
	2. More than job; what they want to do (4)	
Knows me (6)	1. Respects my decisions (1)	1. Interpersonal/technical
	2. My name (1)	2. Technical
	3. "Real self" (1)	3. Interpersonal
	4. Entirely (2)	4–5. Interpersonal/technical
	5. Finds out about me (1)	
Attuned (6)	1. Reads/senses me (3)	1. Interpersonal; Interpersonal/technical
	2. Doesn't forget (1)	2. Interpersonal/technical
	3. Pays attention (2)	3. Interpersonal; Interpersonal/technical

[a]As defined in the introduction, grouped types are interpersonal, organizational, environmental, structural and technical.

up that they felt influenced the quality of care they received, particularly as a current or historic barrier to accessing ideal features of care. Participants described at length providers that "snarled" at them, inappropriately treated them, or refused to touch them or provide services all together in a variety of health care settings. In some participants' views, providers outside of the HIV specialty setting continued to avoid touching clinic cards, or stood at an unnecessary distance. The general belief was that such treatment was the result of societal discrimination due to having HIV/AIDS, being poor, African American, gay or bisexual, or a combination; as one participant explained, some providers only saw her as "HIV." Participants also associated discrimination with wider structural barriers; an undocumented, Jamaican participant expressed his disbelief that he was even receiving care given what he felt was the norm for poor, illegal immigrants (Clinic 1).

Stigma and discrimination also informed a feature of quality of care directly, through the "beyond the scope" (beyond scope) of "normal" care feature. The six participants who responded to being asked about quality of care with descriptions of a "beyond," said that it was "better than it was supposed to be"; that providers went beyond "what they had to do," "what others do," "beyond the medical," and "beyond the job." "Going beyond" also seems to have figured into the sentiments of 5 of the 10 descriptions of "care," by modifying the term with "really," "actually," and "genuinely." Used in this way, "care" was also "quality" because it exceeded the norm. A woman in her mid-20s summed it up as, "They're here for you, like I said, it's not like a regular doctor's office . . . they just *really care*, and it shows" (Clinic 1). In turn, it made participants feel like they were "more than a number," which was another common expression.

"Beyond scope" quality led participants to compare their current care settings with adverse treatment experienced in other clinical settings. One participant who was a patient and also served as a "clinic peer" reported a common sentiment among those with whom she worked:

> Clients . . . have felt the stigma, yeah, basically, and um, they have felt um, being rejected and they've come here. And the complaints I've heard, "I didn't like how they were treating me, they treated me like I was a piece of shit," and um, excuse my French. This place has so much compassion. (Clinic 1)

This quotation conveys the harshness of poor treatment and, in turn, the comparative noteworthiness of good care. It also contains a technique of juxtaposition several participants used, whereby dramatic language, both positive and negative—"piece of shit" versus "compassion"—brought into the same frame the poles of care experiences. Similarly, a White man at Clinic 2 said that his clinic was a "dumping ground" of people who had been treated badly in life (himself included); despite (or perhaps because of) this, he found the nurses who cared for him to be "angelic" (Clinic 2). These depictions suggest a perception among participants that "beyond scope" for them was not better than typically average care, but better than a depressed "average" with which they were familiar based on their social status.

Experiences of stigma and discrimination outside of the clinic or in the past bled into perceptions of the clinical encounter overall. This remained even when participants felt that exceptional care was being performed on their behalves. One African American woman spoke of the need for continued vigilance after receiving an unnecessary and invasive procedure: "We have so much more to think about: How are they gonna treat me? Are they gonna treat me like a person? Are they gonna treat me like a disease? Are they gonna treat me like a guinea pig?" (Clinic 2). She, along with others, noted that discrimination in hospitals and non-HIV specialist settings continued; places of "frickin' jerks" in another participant's words. When asked to describe such people, the participant outlined long-standing practices of "gatekeeping" to

> keep patients at bay . . . people who are obviously really poor, who um, are addicted to various, various addictions, and they're losing . . . [and] you get told you're a piece a shit six hundred times over the course of forty years, you start to wonder if you smell. I've experienced this. (Clinic 2)

This participant takes the consequences of poor treatment a step further. He links being a member of a particular class, the mechanisms of control (gatekeeping and putting down) and its toll on self-worth.

Participating in "Quality of Care"

Study participants described features of quality and, in addition to providing reasons for limited access, conveyed taking part in producing their ideal processes of care. One common formulation was as an exchange, in which a participant gave something and in return received care and treatment. The provided "goods" varied. One was financial, where participants (including those on public assistance) talked about paying for quality services. As one man said, "Everybody plays a role that comes to the clinic. The clinic's gotta get paid. I play a role—the clinic's gotta get paid. It makes no difference [what they get paid] as long as I'm getting my health care" (Clinic 1). Training was another exchanged good, such as up-skilling staff who needed "breaking in" on how to properly vitalize, take blood, and triage in exchange for competent services (Clinic 2). A third form of exchange consisted of giving one's own health management in exchange for care. As one participant explained, "Everybody plays a part . . . I got a big part to play in this . . . if I don't take care of myself, [the services at the clinic's] not going to do me no good" (Clinic 2). Others echoed the sentiment that providers could "only do so much," and the rest was "up to you" (Clinic 3). One woman expressed this as mutually contributing to a shared goal, stating "We need to input for ourselves, and they can put the other half, but we can't expect them to do it all for us . . . [it's] standing alone, together, awesome" (Clinic 1).

Participants also described offering concern for health care staff as a way of building strong exchanges. They said, "If I want respect, I gotta give it to somebody else" (Clinic 3) and "It takes two, right? . . . on the other end of my behavior, I would like me to be nice" (Clinic 2). They extended "trust," "listening," "reliability," "patience," "joking," and "openness to learning." Participants emphasized

the work associated with relationship-building; one female participant stressed, "*I* built that bond [with my provider]!" (Clinic 3) Another began her first interview with, "The whole team, like, I've built a relationship with them," and described how she went about it (Clinic 3).

Some participants redirected their own health management as a gesture of "giving" to the health care environment and did not expect anything in return. For example, a male participant in his mid-40s shared, "I do want to make sure that when I come, everything's perfect, [my provider's] not going to have anything to worry about" (Clinic 2). This participant's description of his self-management resembles his and others' offers of joking, and being nice, as expressed concern for the welfare of the health program and its staff. Similarly, another male participant conveyed that his reliable and biomedically ideal lab results constituted his contribution to "the team" of providers. He was happy to be a "lab rat, in a positive sense . . . what works for me might work for somebody else." Furthermore, he said, he felt that authorities monitored the clinic; if his health was good, the clinic would be viewed favorably (Clinic 2).

Participants also felt they were contributing to a health program's welfare by following clinical rules. Keeping appointments and following service delivery procedures helped the clinic realize its goals of serving everyone. Accepting some delivery inconsistencies further constituted participants' contributions, particularly when it meant care was less than individually optimal. While they were sensitive to being treated with dignity and equity, many felt that it was not realistic to think that services could be the same for everyone all the time. At times, some individuals required more intensive care than others. This frequently came up around long wait times, which vexed participants but, as one said, "Sometimes you realize that a patient may take longer because they might need more support. It used to be frustrating, but then we realized, this person might need to talk . . . " (Clinic 3). Giving way to others meant that, as one participant said, "I took my personal down" (Clinic 2). In one of the most vivid illustrations of linking one's own use of services to the welfare of a health program more broadly, a participant described controlling his visits to ensure there were enough services for everyone:

> I'm from the old school; I don't like to waste, waste not want not. I feel for the economic throes the city itself is in. Why should I come twice a month, when, maybe if I take blood today for example, if I want to know, I can come in interim over three months to find out what the results are; . . . because every time I come, money's spent. I may not be as sick as someone else who may need to come that often. Everybody can't be treated the same. (Clinic 1)

Discussion

Terms Used in Stories

Findings confirm the use but not the sufficiency of thinking of quality of care as discrete, measurable terms. The significant overlap between quality terms and groups as found in the literature (i.e., interpersonal, environmental, organizational, structural, and technical) and used by participants is thrown into question when examining the variety of meaning associated with those terms. They varied across individuals, and in their combined use. Findings suggest that participants may draw from a common set of circulating terms, a point Sinding, Miller, Hudak, Keller-Olaman, and Sussman (2011) also make, and they are best thought of as open to flexibility, descriptive nuance, and personalization.

Most participants chose to embed their terms in personal narratives when given the freedom to select a style of conveying their ideas. Narratives may be particularly appealing vehicles to talk about health (Kleinman, 1988) though research has largely examined its relevance for building patient-provider relationships (Charon, 2008; Greenhalgh & Heath, 2010). Bate and Robert (2007) build upon this potential noting that people also need to make sense of their overall health care. Social interactions (with all providers as well as other health users), intervention activities (procedures, technologies) and the spaces in which they take place (waiting rooms, exam rooms, spaces in between) are all relevant material for crafting stories. It then holds, as it did in this study, that asking about the quality of an individual's care led to rich accounts, explaining what, why and how quality of care mattered within a broader set of experiences.

Dynamic Constructs

Social context strongly mediated participants' notions of quality. They most prominently described the influence of societal stigma and discrimination based on HIV/AIDS status, racism, homophobia, and class rank. This structuring "rationale underlying their expressions" (Sitzia & Wood, 1997, p. 1834) explained their inabilities to access quality of care, an insight supported by substantial evidence of health disparities precisely along these axes (Mahajan et al., 2008; The White House Office of National AIDS Policy, 2011). Participants' awareness of how such attributes shape treatment—as availability and kind—also accords with other studies depicting users as sensitive to forces that influence their circumstances (Allen, Wright, Harding, & Broffman, 2014; Kielmann et al., 2010).

Contextual forces did not only present as fixed barriers to quality of care in the vein of access limitations, but

they were also directly implicated in participants' generation of quality constructs. Quality of care as "beyond scope" (as well as those qualifying "care" in a similar manner) convey how in replacing a subpar, "normal" benchmark for people of their backgrounds with something better—even "angelic"—quality is fundamentally redefined to contain this potential. It is also defined by its precariousness, suggesting that a quality construct is not firm but fluid for those who feel they have experienced stigma and discrimination. Given that part and parcel of these experiences is the stripping of "self-worth," another facet of quality is how deeply affecting it is. In essence, the context of participants' lives, shaping and being shaped by the delivery of care, makes quality dynamic in its formation, and deeply felt.

Co-Production: Actively Making Quality

With the question, "How are they gonna treat me?" always lurking, participants described states of vigilance around how they were being treated, ranging from procedural to social interactions. These descriptions imply that participants on some level mediate contextual forces by constructing and shaping the quality of care they received. The narrative format and varied applications of context complement our finding of participants describing their interventions into services to achieve desired quality of care. The contributions users described making uncannily mirror what they defined as "quality of care," including emotional support, coordination of services, and technical superiority.

The little research on health user participation in clinical activities presents users as self-maximizing (Mallinson et al., 2005; Sitzia & Wood, 1997), or as products of neoliberalism making people more responsible in light of reduced provisioning (Sinding et al., 2011). Though both of these arguments are important, we are directed by participants' insights to consider their forms of engagement as expressions about a common good. We are further struck by the resemblance of their descriptions to an observation offered by Dixon-Woods (2014) of service providers in health care settings who have "practical skills and acquired intelligence to respond to a constantly changing environment" (p. 96). Not only did participants sense they had a role to play in the delivery of quality of care to benefit everyone, but their techniques align with those of providers who are also responding to a complex and uncertain environment.

Sharing strategies resemble the concept of "co-production," developed to envisage civic investment in the delivery of health care and other public provisions (Bovaird, 2007; Bovaird & Loeffler, 2013; Sabadosa & Batalden, 2014; Whitaker, 1980). The model considers health user capacities to "do with" providers, rather than being done "for" or "to" them (Dunston, Lee, Boud, Brodie, & Chiarella, 2009, p. 41). It is notably different from current ideas in the literature on health user involvement, which typically occurs in consultation spaces in which health users can "give voice" to their desired standards of care (Cotterell et al., 2010). Our findings suggest that users' contributions consist of actual work in health care settings, in which they physically articulate their beliefs, values, and concerns about the quality of their care. They collaborate with provider-counterparts through this work.

Co-production challenges a straightforward concept of "self-management," if limited to self-care goals (de Silva, 2011). Indeed, participants showed that personal techniques of health improvement might impact fellow health users, providers, and the health care system. As one participant said, even lab values might contribute to the clinic's standing. There is limited research focusing on self-management as a form of participation, though one study exploring reasons why HIV positive service users stopped going to clinics also found that user perceptions of the greater good may have affected follow-up care seeking decisions (Ware et al., 2013).

Considering the Research Context and Study Limitations

Findings were indistinguishable across the three sites, suggesting that the analysis may offer general learning, but more investigation is needed to determine the applicability for a broader HIV-affected community, as well as other health-seeking communities. The New York HIV/AIDS care landscape is somewhat unique given its well-supported, publically funded delivery of HIV care over the past three decades, a tradition of health user activism, and a mature "consumer involvement" model. The confluence of these factors may be conducive to generating a particular relationship between quality of care, contextual interpretations, and expressions of co-production. The common experience of stigma and discrimination in HIV-affected populations may also make for a particularly "unstable" set of quality constructs.

Given the "field of discovery mode" of ethnography, going forward we advocate testing out the extent to which the analysis holds, and under what circumstances. While qualitative methods are well-suited to capture and analyze complex conceptual and social relationships, future research might include a larger sample and a mixed methods approach to measure health care process variables and health outcomes. It is also important to investigate whether this framework applies to other arenas of chronic health management, as well as in public and private delivery settings. A variety of characteristics—functional skills, clinical attendance—may be associated with participation,

giving the sample an unintended selection bias. Future studies need to better engage those who do not obviously present as involved in health care, especially around conditions in which their involvement is essential for survival. One strength of our methodology is that "everyone has a story to tell" (Bate & Robert, 2007), and future work should capitalize on such inclusiveness.

Conclusion

Despite questions about generalizability, the study remains a significant contribution of an alternative and enriched approach to exploring quality of care from health user perspectives. Returning to the framework analysis, we found the data "fit" with a normative QI approach to studying quality of care, including the importance of contextual influences. However, participants' insights go beyond the limitations of normative research frameworks. Our model has better captured important formative and interactive dynamics around quality, with implications for service delivery. We suggest in future study designs collecting personal and experience-driven narratives to consider how constructs and contexts are situated in dynamic, interpretation-rich relationships. This will enable us to further explore how such relationships influence user-oriented health care practices with effects on health care delivery. Health users are already considered important interlocutors about quality of care, and research that better explores users' "head, heart, and feet" (Bate & Robert, 2007), as processes of co-production, deepen the contributions they can make. In turn, we hope our work sheds new light on how to understand and enact a more patient-centered form of quality of care, and improve health outcomes.

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