Patient Stories Can Make a Difference in Patient-Centered Research Design

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Abstract

Amid increasing interest in improving the patient-centeredness of research, new forms of engagement are emerging that enable researchers to get input from community members on research goals, methods, and implementation. This input often includes stories, which are useful for understanding lived experiences of illness and encounters with health care organizations, and for locating these experiences within larger meta-narratives of specific communities. We analyzed the stories in transcripts of 13 Community Engagement Studios and identified 4 major functions that the stories served in the sessions. Major functions included: (1) establishing mutual understanding, (2) adding expansion and depth, (3) characterizing abstract concepts, and (4) providing context for experience, with the latter being the most frequent. We assert that stories can serve to better communicate the complex contexts of patient experiences, helping to align research priorities and research design with community interests, leading to more patient-centered innovations in clinical practice.

Keywords

storytelling, patient-centeredness, research design, community engagement

Introduction and Background

As the health care industry strives to improve the patient-centeredness of care (1–3), there has also been interest in improving the patient-centeredness of clinical research, evidenced by US Congressional reauthorization of the Patient-Centered Outcomes Research Institute (PCORI). Proposals for funding through PCORI and other agencies now require that patient representatives be part of the research team, and that meaningful patient input is sought before designing the study. These are strategies to improve the extent to which research pursues questions that are important to patients. However, in the pursuit of meaningful input for research design, investigators are often hampered by their own biases and communication skills.

Meanwhile, health research organizations are expanding their resources in the field of community engagement (4), which specializes in this type of translation. Community engagement specialists facilitate focus groups, studios, and other communicative formats for obtaining input from

communities that investigators can use to improve research design and implementation (5). The sessions aim to assist the

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investigator in gaining a fuller perspective on the individuals' experiences with life and illness, and to assist the community members in providing input to the research design process—which often takes the form of telling stories from their everyday lives.

People often share information in the form of stories, using conceptual resources and artifacts at hand to interpret experiences and produce coherent narratives and explanatory models (6). Stories convey human experience in a way that reflects subjectivity (ie, the teller's perspective) and intersubjectivity (ie, connections to listeners and readers). Stories are useful for understanding individual experiences of illness (7,8) and encounters with the health care system, and for locating these experiences within larger meta-narratives of specific communities.

Patterns in patient experiences that reflect cultural context can be useful in designing policy and institutional improvements to health services, and in research design. Researchers are influenced by many factors as they design studies, including the priorities of funders, their training and mentors, and research collaborators (eg, biostatisticians, behavioral scientists, other clinicians) who bring specialized knowledge to the design. This article reports on findings from an investigation into the functions of storytelling in studios where community members provided input on the design of research projects. With this analysis, we hope to stimulate discussion on how patient stories can improve the patient-centeredness of research at all translational stages.

Methods

Data

This study was approved by the Vanderbilt University institutional review board. The data for this analysis come from a larger study that compared two types of research studios. Studios are consultative group sessions during which researchers receive input on a project proposal or design. With the goal of refining the definition of patient-centeredness in research (5,9), we randomized investigators seeking input on their research designs to either a Community Engagement Studio (CE; a panel of community members or patients; 5) or a Translational Studio (a panel of other researchers) (10). For this article, we analyzed transcripts from 13 CE Studios. Each Studio was convened for a specific project. Studio participants were recruited through outreach to community centers, neighborhood associations, community health centers, faith-based organizations, and adult education services. Studios were facilitated by staff from the Meharry-Vanderbilt Community Engaged Research Core. In each, the investigator gave a short presentation describing their proposed project and inquiries on which they sought feedback. The CE Studio model uses a trained facilitator, often a community partner, who has experience working with diverse stakeholder groups and balancing power dynamics. The facilitator guides the discussion to

ensure that the investigator's inquiries are addressed and the voices of all panel members sought. Facilitators did not coach or guide the participants on how to provide feedback, that is, they did not explicitly ask participants to tell stories. The studios were recorded and transcribed for analysis.

Data Analysis

Using qualitative methods, we coded the transcripts from the studios to identify stories and their functions in the session (11). Coding involves highlighting excerpts of text in a transcript and labeling the excerpt with one or more codes, or themes. Codes can emerge through a process of open coding (12) that enables the coders to identify all themes that apply to the data, or existing theories or frameworks can be used to supply a set of themes. We were unable to identify an analytical framework for storytelling that was sufficient for this case (the functions of stories in a group environment). Therefore, we started with a basic definition of a story to enable identification and used thematic analysis (13) based on our ethnographic training and experience to define their function in the studio. A story is an account with a beginning, a sequence of unfolding events, and an ending (14). We further defined stories as narratives with (a) at least one actor, (b) action that unfolds over time, and (c) a realization, destination, or conflict resolution. For example, "I refilled my mother's pillbox on Sunday, and on Friday I found the pillbox still full" would be a story; however, "my sister isn't interested in getting a mammogram" would not. In the transcripts, 235 excerpts were coded as stories by one researcher (C.S.) and reviewed by a second researcher (L.L.N.). The 2 researchers then coded the stories for *how* they facilitated communication in the Studio using an open-coding style; that is, we did not apply a specific interaction or communication theoretical framework. It was possible for any given story to have more than one code applied to it; that is, stories were not classified in a mutually exclusive way. Disagreements in classification were resolved through discussion.

Results

The 100 individuals in the 13 CE Studios were patients, caregivers, community providers, or patient advocates identified by their health status, health condition, or demographic characteristics based on the project-based needs of the researchers. Health conditions included diabetes, heart failure, Parkinson disease, Sickle cell disease, and intensive care unit survivors. Table 1 describes the topics of the studios.

We found 4 major functions of stories in the Studios, described in Table 2. They included (1) establishing mutual understanding, (2) adding expansion and depth, (3) characterizing abstract concepts, and (4) providing context for experience, with the latter being the most frequent. Speakers provided the context in a wide variety of domains, ranging from the context of the body to spatial and institutional contexts. As previously noted, a particular story may have

Table 1. Community Engagement Studio Topics, Participants, and Focus.

Research topic	Community engagement studio participants	Studio focus
Deep brain stimulation in early stage Parkinson disease	Men, age 50-65 with Parkinson disease diagnosis for 4 years or less (n = 7)	Research ethics, implementation, research design, recruitment
Symptom management smartphone application for head and neck cancer patients	A diverse group of patients with chronic conditions where the pain is a factor (n = 7)	Consent, implementation, intervention design
Improving healthcare systems	Patients who have been hospitalized in the previous 3-5 years and have experienced adverse events/s that impacted care (n = 9)	Research design, implementation
Exploring patient and provider perceptions of the needs of patients with Sickle cell trait	Individuals who have the sickle cell trait or are caregivers for people with the trait (n = 7)	Recruitment, research design
Center for excellence in precision medicine and health equity	Hispanic adults (n = 8)	Implementation, dissemination
Community assessment of a REDCap-based model of eConsent	A diverse population of patients. (n = 9)	Consent documents and process, ethical considerations
HIV+ adults not engaged in care	Individuals who have been diagnosed with HIV/AIDS who have a history of poor adherence and noncompliance (n = 5)	Ethical considerations, program design
Social and behavioral determinants of health and missed HIV health care provider visits	A diverse group of patients (n = 7)	Ethical considerations, implementation, recruitment
APOL 1 genetic testing in African Americans	African Americans with kidney disease (n = 9)	Ethical considerations, recruitment
Assessing the educational needs of ICU survivors	ICU survivors and caregivers (n = 10)	Program design, implementation, dissemination
Diabetes stigma	A diverse group of individuals with type 2 diabetes (n = 8)	Survey design
Patient engagement in breast imaging	A diverse group of women older than 40 (n = 9)	Ethical considerations, program design, implementation
Improving oral health and diabetes outcomes	Dental providers and insurance representatives who serve at-risk and predominantly African American communities (n = 5)	Research design, implementation, recruitment

Abbreviation: ICU, intensive care unit.

been coded with more than one code. For example, many stories involved people with whom the participant had relationships. In some cases, that relationship was a key part of the context of the participant's experience (see examples in the "Relational" category in Table 2). In other cases, the relationship was relevant, for example, motivated action, but did not provide context for the participant's experience of an event or situation. Therefore, some examples in Table 2, like many excerpts, may represent multiple domains but are presented here as exemplary of a particular domain.

Discussion

There has been a long-standing interest in storytelling in medical and social science research (8,15–18), and our contribution explores how participants used storytelling to communicate contextual aspects of lived experiences. We often engage community members in research for their expertise as patients, caregivers, or community members, and their experiences of health care and social determinants of health in community contexts. Yet, reflexively, we may expect

them to share their expertise in a manner that is consistent with a scientific, explanatory framing and language, that is, using impersonal language, focused on a logical explanatory approach including dimensions of cause and effect. This is not how the average person communicates.

A strength of our study is that we used qualitative methods to access the contextual factors that contribute to the patients' construction of meaning, making associations we might not have otherwise observed. For example, the linkage between breast cancer screening and family tensions about inherited disease, or subtle paternalism experienced by patients who must adhere to an arbitrary, insurance-driven schedule of care are instances of such meaning-making. These associations can inform both researchers and those who provide research leadership and make funding decisions (eg, funding agencies, deans, and department chairs), establishing the availability of resources for individual investigators. For example, stories can elucidate how processes unfold, and this can serve as the basis for further inquiry. Participants' stories about challenges managing frequent appointments during their working hours are clues to

Table 2. Functions of Stories in Community Engagement Studios.[a]

Function	Description	Examples from Studio discussions (stories in italics and boldfaced for emphasis)
Establishing mutual understanding	Establishing mutual understanding, providing reasons and priorities, responses to specific questions	Prompt: What are some of the factors that pushed you to get a mammogram? *I think mine was because my first cousin had breast cancer and she got it at like 29, and she didn't know that she needed to get a mammogram. She found a mass and when she went and got a mammogram, she had breast cancer.* [Answering the specific question with a story] Prompt: Why did you or the person you love not do what they were supposed to do even though the doctor said, "This will make you healthier," or "This will keep you healthy?" How do we address that? Participant: Sometimes it is painful to do what the doctor says to do, physical pain. A lot of people resist physical therapy even though they know it's going to be good for them because it hurts. Participant: I think it depends on, too, how sick they are. *My nephew died last year from scleroderma. When he got that diagnosis, and the doctor said his life was going to be like three years, and he keyed in on the three years. So, he didn't do a lot of taking his meds and going to the doctor and everything.* I think it depends on what their diagnosis is and what they are going through. [Using a story to explain one reason why a person might not be adherent to treatment]
Expansion and Depth	Moving the discussion by expanding on a point, adding detail, or adding a new dimension	Prompt: How can we take the stress of the financial part of it off the caregiver? That's a big question. *I don't think it will, because I care for my sister. Fortunately for her, she has [insurance], and so far they have paid for everything because she just got out of [hospital]. She had been there for like nine days. The financial burden, as far as the medical side of it, is okay, but as far as the things we have to do for her, because now she is at home on oxygen and we are doing all these things to try to keep her from smoking. But I think the emotional burden on caregivers, knowing what she is going through, and bringing her in and out of the hospital . . . we bring her to the E.R. and they send her straight to the ICU and they might keep her for a day or two. This is just a constant in and out.* [Using a story to expand the question of the financial burden to include the associated emotional burden]
Characterization	Providing examples of abstract ideas	*At the new place, we got our floor, we got our place, so it is more discreet than it was, but if it was not for the discreetness, I don't think a lot of people would come to doctors' appointments. It is a big social stigma.* [Giving a specific example of what "discreet" means in the context of a specific stigmatized illness]
Providing context for experience	Helping others understand how a phenomenon is experienced with respect to a specific contextual domain	See the specific contextual domains below.
• Context of the body	Bodily experiences and interpretations of them	*People keep telling me it's not as bad anymore, but I felt that when I had an abnormal reading it was because of something they did because of the way that they handled my breasts. I just didn't like that. I've just not gone back.* [The body is a central element of the person's experience of mammography and why she has not returned]
• Emotional	Experiences of fear, frustration, and other emotions	*I took mine and I went home, and when I went back for my doctor's visit, they said it was fine, but the time between then, I didn't know . . . and I didn't know it was normal to wait. I had a screening, and I was in this screening population, but I didn't know any of that information. It is nerve-wracking, and you're thinking, "You sent me [for this screening] because of this, this, and this, and now I have nothing until I get to the doctor's office." We live in the Information Age when everything is so quick, so why is it taking so long?* [Emotional experience is labeled "nerve-wracking" along with details about the wait for results]

Table 2. (continued)

Function	Description	Examples from Studio discussions (stories in italics and boldfaced for emphasis)
• Everyday life	Embedding illness experiences in processes or daily activities, eg, work or school	*I work in an industry where I have a very flexible schedule if you are only asking off for four hours once every so many months versus two hours this week and then two weeks later because then they start to question, "What's wrong with you?"* [Managing illness in the context of a job] Another participant: *When I was at my job, I was buying a house, and for two months, I didn't have a home. I literally was homeless and my adherence went down 50%...* [Daily context of homelessness influenced illness-related activities]
• Identity	The context of the self	*I have had a couple of start-stops going on for various reasons. Some of those are my fault, my choice. I just wasn't ready to get into the fact that this is part of my life now.* [Description of how one's identity must shift to include the illness as an aspect of one's life]
• Institutional	Experiences of biomedical or other institutional context	*My gynecologist really didn't leave it open for debate. She just said, "Here is your appointment. You need to make your appointment to come back and see me one year and one day after today, and then you can't go back and see them until one year later."* [Detailed interaction with a health care provider and implications of an insurance policy]
• Initial experience	First experience of illness, eg, diagnosis	*I just had some tests done, just routine labs, and she got an A1c. She called me back and my doctor always mails me my lab results. But she called me and said, "Your A1c is [high]," and I said, "No it's not."* [Initial reaction of denial at discovering an illness is present]
• Relational	Relationships and their impacts on the topic being discussed	Participant: This is a hard one on me because I am the only boy in my family. I see that most women keep up with it more than men. I don't know why. Now, my sisters, they are like, "I ain't going to the doctor!" Ever since I was 10 or 11 years old, if I have a toenail hurt, I am going to go to the doctor and see about it. I don't want anything to slip up on me. Some women... I ain't sayin' like y'all, but my family - they won't go to the doctor. *I got two sisters right now. They've both got cancer, and they just found it, and one of them is 41 and the other one is 32. When momma passed away, they feel like I should be the one to tell them. I can't tell y'all. Y'all need to take care of yourself!* [Participant reveals his careful approach to health and the burden he feels in the unwelcome responsibility for his sisters' health]
• Spatial	Experience in physical spaces	*This last time I went... I wasn't brought into the room with the robes. I was just ushered straight into a mammography room... That felt oddly isolating; in some ways being in the room with the other women was oddly comforting to know that I wasn't the only one stressed out over this or having to do this every year or every six months.* [The group waiting room was a source of comfort and social support]

Abbreviation: ICU, intensive care unit.
[a]Example stories from each category are in bold text. Additional text from other Studio participants is included to demonstrate the role of the story.

1442

potential ways to improve services, for example, through an off-hours clinic. Improving access to care can improve outcomes, and stories help us understand how access to care is navigated in everyday life.

A second strength is that stories can help identify community priorities relevant to research that are embedded in community narratives. This may help institutions better align priorities with community needs and improve outcomes. For example, health care organizations providing clinical services to patients with a stigmatized illness may not understand how that stigma plays out and that it includes patients' experiences in clinical settings. As we show in the Characterization domain, stories can help make abstract concepts like "discretion" more concrete.

A third strength is that insights from stories can contribute to improving research community engagement activities, and to the design of clinical research to reduce the burden on participants and remove other barriers to participation. The findings presented here are the result of rigorous qualitative analysis. The themes reflect the categories we ascertained after a process of classifying stories and then consolidating themes in a way that minimized redundancy while describing the variety of experience contexts. Our themes have fidelity to our data but can be useful to others designing research and quality improvement initiatives. We also hope to draw attention to the value of examining stories rigorously and using themes to inform research design and institutional quality initiatives. Therefore, actionable efforts that might improve patient-centeredness would first involve recognizing the importance of stories and establishing mechanisms such as Community Engagement Studios that enable listening to stories. With attention to the content of the stories, investigators can then build elements into research design that address the issues identified. For example, in the domain of Expansion and Depth, a participant describes compelling emotional challenges in assisting a family member through a difficult illness. An investigator could use this information for further inquiry and the possible inclusion of a caregiver support intervention into a clinical trial.

Our study involved several limitations. The Studio participants were all recruited from Middle Tennessee; regional influences may have influenced storytelling. The number of participants in each individual Studio was relatively small. Nevertheless, the strength of our study is that we set forth a preliminary framework for the role of stories in community engagement for research that can be evaluated further.

Conclusion

Our findings demonstrate that the stories of community members and patients can provide a rich resource for research institutions and individual investigators to better align research design with community priorities. This alignment is not something for research institutions to pursue only out of altruism; there is a 2-way benefit. If research can be better aligned with the needs of patients, caregivers, and other community members, the findings and innovations resulting from that research can be more successfully implemented in clinical practice.

Authors' Note

Declaration of Conflicting Interests

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Laurie Lovett Novak, PhD, MHSA teaches and conducts research as assistant professor in the Department of Biomedical Informatics at Vanderbilt University Medical Center. She is an anthropologist specializing in the cultural intersection of technology, work, and everyday life. Dr. Novak's research has focused on everyday experiences of chronic illness and the design and implementation of technology in clinical settings.

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Sarah Stallings, PhD is research assistant professor and operational lead for the Precision Medicine and Health Equity Center at the Meharry -Vanderbilt Alliance. Her role is facilitating research and broadening community engagement across the entire research cycle.

Jabári S Ichimura is a research coordinator with the Vanderbilt University Medical Center Wilkins Lab where he project manages and coordinates multiple projects in the areas of health equity, precision medicine, public & community health, and clinical trials. He has a diverse clinical and research background, having held roles in Clinical Trials at the Vanderbilt-Ingram Cancer Center (VICC) and as a lab technician and nursing assistant while completing his education in Biology and Nutrition.

Consuelo H Wilkins, MD, MSCI - a geriatrician, clinical investigator and engagement researcher - is Vice President for Health Equity at Vanderbilt University Medical Center, and Professor of Medicine, Vanderbilt University School of Medicine.