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The complexity of patient participation: Lessons learned from patients' illness narratives☆,☆☆

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Abstract

Objective: To describe the meaning of active participation from the patient's perspective.

Methods: We used a narrative framework to analyze transcripts generated from 16 qualitative open-ended, semi-structured interviews with primary care patients in Houston, Texas.

Results: Patients' illness narratives reflected several themes related to patient participation. These included patients' perspectives of illness (i.e., how central the illness is in the patient's overall life story and how changeable the patient believes their illness to be) and aspects of actions pursued in the context of patients' illness narratives (i.e., the degree of illness-related activity that a patient engages in and the role of partnership with the patient's physician in health decision making and illness management). The relationships among these themes explained a limited number of distinct illness-management strategies pursued by patients.

Conclusion: Our findings revealed a level of complexity to patients' healthcare participation that has not been previously described. Patients' illness-management strategies were explained by four thematic story elements in dynamic interplay with unique variations for each individual. Further research is needed to explore how these story elements influence communication between patients and physicians.

Practice implications: By understanding the nature of and relationships between the thematic elements in patients' illness narratives, practitioners will be able to better inform their negotiations with patients regarding participation in healthcare.

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1. Introduction

Patient participation in healthcare activities is a concept that has been receiving increasing attention [1,2]. The Institute of Medicine, in its call to improve quality in the US healthcare system, described the patient as an important "source of control" and suggested that patients assume "the degree of control [that] they choose over health care decisions that affect them" [3]. Patient self-management and monitoring of symptoms and treatment processes has been shown to improve outcomes in the setting of chronic illness, and a number of strategies have been proposed to facilitate such activities [2,4–7]. Active patient participation in the medical encounter has been demonstrated to result in better disease control, higher patient satisfaction, and improved physician communication behaviors [8–14]. Patient engagement in healthcare has also been proposed as an important strategy to reduce medical errors [15]. In general, these literatures on self-management, patient–physician communication, and

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medical errors suggest that patients should take a more active role in their health than currently occurs, and that systems should be developed to foster such activity.

A problem with the literature is that patient participation is often framed from a biomedical perspective (i.e., focused principally on disease management). This may not be consistent with patients' perspectives on participation in the healthcare process. Limited data about patients' perspectives of active participation suggest not only variability in the extent to which patients wish to participate [16–19], but also barriers to participation [6,20] and the need for physicians to adopt new paradigms with respect to patient participation [21–24]. For example, how do patients describe and view participation in their own healthcare? What meanings do patients ascribe to active participation? In this study, we used a narrative framework to examine patients' illness stories and describe the meaning of active participation from the patient's perspective.

2. Methods

We analyzed 16 transcripts that had been generated from semi-structured, open-ended interviews conducted during the first phase of Project CONgruence Network Exceed Communication Team (CONNECT). Project CONNECT was a multi-phase, multi-method study of cross-cultural communication in primary care settings in Houston, Texas [25]. In the first phase of Project CONNECT, patients with primary care appointments at public (The DeBakey VA Medical Center) and private (The Kelsey-Seybold Clinics) healthcare settings were invited to participate in an interview about their illness experiences. Three interviewers experienced in qualitative interviewing conducted all interviews. Interviews lasted between 20 and 60 min in length, and were conducted either in the participants' usual medical clinics, their place of work, or their homes. The interviewers used guiding questions and probes based on Kleinman's 'eight questions', which were originally proposed to help clinicians to conduct 'mini ethnographies' in the setting of patient care [26]. After obtaining informed consent, the interviewers audiotaped all interviews, the interviews were transcribed by a professional transcription service, and each was read and initially discussed by the authors, who comprised the analytical team.

We used a narrative framework to guide our analysis. This framework is based on the notion that humans often communicate meaning through the use of stories [27]. In narrative analysis, researchers pay special attention to story elements (e.g., who are the characters?, how are they positioned in the story?, what is the plot of the story?, when does the story begin and end?, what is the context and setting in which the story is situated?, etc.) in order to understand the meanings that are embedded in stories that subjects tell [28–30].

For our analysis, we focused initial attention on six transcripts that we selected as representing a range of patient involvement and participation. We followed a series of over 20 iterations of individual reading, notation, and group discussion of these transcripts, spending more than 40 h in group discussions. We documented these discussions with a series of analytical memos, transcript coding, and graphical representations, all facilitated by Atlas.ti qualitative analysis software. From these discussions emerged four conceptual themes (described below) pertaining to patient participation.

Next, we divided the 10 additional transcripts among ourselves, and individually read these transcripts in the context of our conceptual themes, again using a narrative framework. We discussed these individual readings during 10 additional hours of group discussion. No new themes emerged during analysis of the ten additional transcripts. During these discussions, we developed a conceptual framework that described relationships among themes, and used this framework to explain each interviewee's participation in their care, thus affirming that the conceptual framework was germane to each participant in the CONNECT phase 1 qualitative study. We chose representative quotes pertaining to individual themes, and one patient's story to illustrate our conceptual framework.

3. Results

3.1. Study population

The 16 participants' ages ranged from 30 to 81. Ten of the participants were male. Four participants reported African American, five reported Hispanic, and seven reported Caucasian ethnicity. Participants reported incomes ranging from US$ 5000 to 75,000 annually, with the majority of participants reporting annual income between US$ 30,000 and 40,000. The highest educational level completed by participants ranged from 8th grade to a masters' degree, with the majority of participants reporting completion of high school.

3.2. Four themes related to patient participation

Patients' illness narratives reflected four common themes related to patient participation. Two themes described patients' perspectives of their illness. These were: (a) *how central the illness is in the patient's overall life story*, and (b) *the perceived degree to which the illness plotline can change for the better.* Two additional themes described aspects of actions pursued in the context of patients' illness narratives: (a) *the degree of illness-related activity that a patient engages in*, and (b) *the role of partnership with the patient's physician in health decision making and illness management*. Below, we present examples of each of these themes.

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