Title:
Collaborative Work of Patients and Providers: Symptoms, Challenges, Shared Meaning, and Planning the Work

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Session Title:
Research Poster Session 1
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Abstract Describes:

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Adaptive Leadership, Chronic Hepatitis C and Self-management

References:


Abstract Summary:
Patients with Chronic Hepatitis C face treatments that worsen the unpleasant symptoms they experience from their disease. We used the Adaptive Leadership Framework for Chronic Illness to explore how healthcare providers collaborate with patients to share treatment information and whether the way it’s shared influences patients’ self-management of symptoms.

Learning Activity:
**LEARNING OBJECTIVES**

| The participants will be able to describe components of collaborative work between patients and providers | Describe components of collaborative work between patients and providers. |
| Participants will be able to apply the concepts of collaborative work to your patient population. | Apply the concepts of collaborative work to your patient population. |

**Abstract Text:**

**Purpose:** Patients with CHC face treatment regimens that worsen the already unpleasant and sometimes debilitating symptoms they experience from the disease, including fatigue, depression, fever, poor appetite, nausea, vomiting, abdominal and joint pain (Fusfeld et al., 2013). We used the Adaptive Leadership Framework for Chronic Illness to explore how healthcare providers work with patients to share treatment information and examine whether the way it is shared influences patients’ symptoms and self-management over time. The Adaptive Leadership framework, originating in business (Heifetz) has recently been applied in healthcare to describe technical challenges as ones that have known technical solutions that can be mediated by the expertise and authority of a clinician (Adams, Bailey, Anderson, & Thygeson, 2013; Bailey et al., 2012). On the other hand, adaptive challenges are complex in nature, are easy to deny, and require a the patient to adapt, learn or change their behavior in some fashion (Thygeson, 2013). In earlier work, we expanded the framework specifically for chronic illness to reflect the dynamic nature of symptoms and challenges and to characterize the events that create the need for patients and families to engage in adaptive work (Anderson et al., 2015). Adaptive work is defined as developing and using the skills and actions required to change behavior and overcome adaptive challenges (Anderson et al., 2015). Our framework also proposes that the best plans of care for self-management can be developed through collaborative work, defined as patients and family members working together with the provider to jointly develop the most effective approaches for adaptive work by monitoring symptoms, assessing the challenges, verifying shared understanding of symptoms and challenges, and planning the work. The purpose of this study was to explore how healthcare providers interact with patients to share treatment information (collaborative work) and whether the way it’s shared influences patients’ symptom self-management.

**Methods:** This descriptive mixed methods study was part of a longitudinal case study of patients and their providers as they engaged in aggressive treatment for Chronic Hepatitis C. Data includes patient participant interviews following the initial and final clinical encounter; these office visits were recorded and transcribed verbatim. Follow-up interviews were conducted by telephone over the 12-24 weeks of treatment. The patient also completed a measure of patient activation at each time point. We interviewed the provider following the initial encounter and after the final clinic visit where treatment results were shared with the patient. Textual data reporting provider notes and records of phone contacts with the patients were abstracted from the electronic medical record. Data collection is complete.

We are analyzing the data of patient provider interactions using responses from patients and providers during these encounters and interviews following these encounters. We are identifying the conditions under which we see examples of patient/provider collaboration (collaborative work) and coding these using the concepts from our framework. They are: 1) monitor symptoms, 2) assess challenges, 3) verifying shared understanding of symptoms and challenges, and 4) plan the work. We will further describe the collaborative work for depth by quantizing the data, using a Likert type scale. For example, collaborative work that is limited to monitoring symptoms only would be scored lower than collaborative work that included higher levels of engagement such as assessing challenges and joint planning. We are also analyzing the scores from the Patient Activation Measure (PAM) collected at each data collection time point.
**Results:** Our 20 cases include 13 men and 7 women participants with an average age of 55 (Range 42-65.) The sample was 50% (10) African American. Healthcare provider participants were 5 MD, 3 PA’s and 2 NP’s. In our preliminary analyses we found multiple examples of patient participants and their healthcare providers monitoring symptoms. However we found few examples of providers assessing these symptom challenges for their patients and even fewer examples of providers and patients verifying share understanding of challenges and interacting to plan the work of self-management during treatment. Preliminary analyses scores on the Patient Activation Measure (PA) varied across the treatment period. Most participants reported a downward trajectory on the PAM suggesting that as symptoms increased, patient’s ability to self-manage decreased. A small number of participants reported a mixed trajectory e.g., as symptoms fluctuated, patients’ ability to self-manage increased or decreased. Quantizing of the qualitative data is underway and will be completed and presented in this paper.

**Conclusion:** This study is the first to explore the collaborative work of patients and their healthcare providers while undergoing treatment for CHC. Findings from this study underscore the importance of developing new self-management interventions and care models for mobilizing support for monitoring symptoms, assessing challenges, and planning the work.