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

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This study was supported by research grants (NIH/NINR: 1 R21 NR 013461, D.E. Bailey Jr., PI & P30NR014139, S.L. Docherty and D.E. Bailey Jr., MPI, Duke University School of Nursing.

BACKGROUND & PURPOSE

Patients with Chronic Hepatitis C face treatments that worsen the unpleasant symptom of fatigue that they experience from their disease. We used this symptom and the Adaptive Leadership Framework for Chronic Illness to explore how healthcare providers collaborated with patients to share treatment information and whether the way it's shared influenced patients' self-management of fatigue. The process involves engaging providers, patients, and families in developing shared understanding of symptoms, responses to the symptoms, and associated challenges to develop a shared meaning. These are the basis for jointly developing care plans to address challenges (might be owned by patient, family members, provider). The care plan is translated into technical and/or adaptive work for patients, and families to support symptom self-management of fatigue.

METHOD

Longitudinal mixed methods descriptive case study

Data sources:
- Patient and provider interviews following initial and final clinical encounter;
- Follow-up interviews conducted by telephone over 12-24 weeks of treatment;
- Patient activation measure (PAM) completed each time point to measure self-management;
- Textual data of provider notes and phone contacts abstracted from HER

ANALYSIS

- A priori codes from framework and emergent codes
- Z-scores used to plot PAM

FINDINGS

Monitor symptoms

Assess challenges

Shared meaning of symptoms & challenges

The Adaptive Leadership Framework for Chronic Illness

PARTICIPANTS & SETTING

Patient Participants:
- 13 men and 7 women with CHC (mean age=55; range 42-65)
- 10 African American
- 10 Caucasian

Provider Participants:
- 5 MDs, 3 PAs, 2 NPs providing care for CHC patients

Setting:
- Care provided in the Duke Liver Clinic or Boice-Willis Clinic

SUMMARY:

This study underscores the need for next generation self-management interventions and care models to support the collaborative work of patients and their healthcare providers while undergoing treatment for CHC. While patients and providers monitored symptoms they did not collaboratively assess challenges and we found no evidence of providers working with patients to plan work that incorporates evidenced based strategies to self-manage fatigue.