

Title:

Future Research Design Implications of Clinician and Patient Engagement for People with Heart Failure

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Session Title:

Conducting Patient-Centered Comparative Effectiveness Research: Exemplars From the Field

Slot:

G 19: Monday, 30 October 2017: 1:15 PM-2:30 PM

Scheduled Time:

1:15 PM

Keywords:

patient engagement, research design and methods and rural hospital

References:

Fleurence, R., Whicher, D, Dunham, K., Gerson, J., **Newhouse, R.**, Luce, B. (2015). The Patient-Centered Outcomes Research Institute's Role in Advancing Methods for Patient-Centered Outcomes Research. *Medical Care*, 53(1), 2-8. Doi: 10.1097/MLR.0000000000000244.

Newhouse, R.P., Johantgen, M., Thomas, S., Trocky, N., Dennison-Himmelfarb, C., Cheon, J., Miller, W., Gray, T., Pruitt, R. (2017). Engaging Patients with Heart Failure into the Design of Health System Interventions: Impact on Research Methods. *Geriatric Nursing*, in press.

Sofolahan-Oladeinde, Y., **Newhouse, R.P.**, Lavalley, D.C., Huang, J.; Mullins, C.D. (2017). Early Assessment of the 10-Step Patient Engagement Framework for Patient-Centered Outcomes Research (PCOR) Studies: The First 3 Steps. *The Journal of Family Medicine*, in press.

Abstract Summary:

People with heart failure in rural settings are under-represented in research studies focusing on their care. This presentation describes clinician feedback and interviews conducted with people admitted with heart failure to two rural hospitals that informed research design and methods of a subsequent study.

Learning Activity:

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
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Describe one patient engagement approach (interviews) to inform decisions about research design, methods and outcomes when planning a study.	Introduction, research study design, setting sample procedures results
Discuss the implications of patient engagement to improve research design and methods.	Lessons learned from the voice of the patient, changes to research design, methods and outcomes, comparison and contract of changes to research design based on stakeholder/clinician engagement and patient engagement

Abstract Text:

Background: People with heart failure in rural settings have been under-represented in research studies focusing on their care. Furthermore, few studies have engaged clinicians and patients to inform the design and methods used. If research focuses on areas that are important to patients, clinicians and stakeholders -interest in participating in research as well as translating the results of research to practice would be enhanced.

Purpose: The purpose of this study was to assess if changes are needed in a research study design, methods and outcomes when transferring interventions used in a multisite urban/community study to rural hospital settings through clinician and patient engagement with people with heart failure (HF).

Design, Sample and Setting: A working session was first conducted with stakeholders (six Registered Nurse clinician study team members) to review the study protocol, discuss the clinical context and determine if protocol changes were needed. Next, structured interviews were conducted with HF patients admitted with a diagnosis of HF to determine if additional changes to the protocol were required. The setting was two rural hospitals.

Method: Changes to the protocol were made after stakeholder engagement based on group consensus. Next, eight patient subjects completed structured interviews. A content analysis of theme responses was summarized by frequency.

Results: Stakeholders recommended three changes [add health literacy assessment (vs education completed), add medication adherence questions post discharge and delete the patient HF knowledge post-test). Patients verified the recommended changes obtained from stakeholder engagement, but identified **one** additional area that should be added to the study protocol (symptom experience).

Conclusion: Stakeholder and patient engagement validated that the intervention, methods and outcomes were important, but four changes to the protocol were recommended before study implementation.

Implications: Including the perspective of stakeholders and patients is essential to guide investigator approaches to design, methods and outcomes in pragmatic studies. Stakeholder and patient engagement has a significant role in designing implementable pragmatic studies whose results are important to clinicians and patients.