

# Involving Patients and Caregivers in KT Research: Issues and Perspectives from a US KT Researcher

Heather Schacht Reisinger<sup>1,2</sup>

<sup>1</sup>Iowa City VAMC <sup>2</sup>University of Iowa

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# Overview

- Patient (and Provider) Involvement
  - VA Project to Implement Diuretics
    - Patient-activation intervention to increase the use of thiazide diuretics (guideline-concordant therapy) among hypertensive VA patients
- Caregiver Involvement
  - VA Outreach Study
    - Ethnographic formative evaluation to improve VA outreach to returning service members and their families

# VA Project to Implement Diuretics

- Evidence-based guideline: Thiazide diuretics as first-line therapy for uncomplicated hypertension (ALLHAT; JNC-7)
- Intervention: An individualized letter with past BP, current BP medications, and a suggestion to the talk with their PCP about prescription of a thiazide diuretic
- Methods: RCT to test the efficacy of the intervention and semi-structured interviews to examine process and patient and provider perspectives of the intervention

# VA Project to Implement Diuretics

- Aim 1: Increase number of patients who bring in the letter and prescribed thiazide diuretic.
- Aim 2: Increase PCPs' prescription of thiazide diuretics.

# RCT Results

- 67.1% of intervention patients (n=556) discussed a thiazide with their PCP
- 25.9% of intervention patients were prescribed a thiazide
- “Contaminated” controls (n=184) were more likely to be prescribed a thiazide than pure controls (n=103)

# Why did the intervention work?<sup>1,2</sup>

- Overall both patients (n=34/41; 82.9%) and providers (20/21; 95.2%) had a positive perception of the intervention
- Patient perspectives of participating
  - Straightforward and easily understood
  - Sense of obligation

<sup>1</sup> Pilling SA, Williams MB, Brackett RH, Gourley R, Weg MW, Christensen AJ, Kaboli PJ, Reisinger HS. Part I, patient perspective: activating patients to engage their providers in the use of evidence-based medicine: a qualitative evaluation of the VA Project to Implement Diuretics (VAPID). *Implementation Science*. 2010 Mar 18;5:23.

<sup>2</sup> Buzza CD, Williams MB, Vander Weg MW, Christensen AJ, Kaboli PJ, Reisinger HS. Part II, provider perspectives: should patients be activated to request evidence-based medicine? A qualitative study of the VA project to implement diuretics (VAPID). *Implementation Science*. 2010 Mar 18;5:24.

“I figured if you’re doing a study there’s a purpose for me to do all this stuff and, and I don’t have to know the reason necessarily, it’s just that it was no big imposition on my part.”

--Patient

# Why did the intervention work?

- Patient and PCP perspectives
  - Involved, well-defined patient role
  - Aligned patients and PCP goals
  - Informative, educational discussion
- An unintended (and unmeasured) outcome?



“I think it’s a great idea...for many reasons. The actual subject matter, of course, is very pressing. Poorly-controlled hypertension is a well-recognized problem, and under-utilization of diuretics. And it’s also um, a nice intervention to involve patients and empower them. ... It’s wonderful to get the patients involved directly in their care, and uh, inform them of the goals and methods of achieving those goals.”

--Primary Care Provider

# VA Outreach Study

- Ethnographic formative evaluation of a local “intervention” responding to a national mandate (without evidence-base)
- Observations of outreach events and in-depth interviews family and service members, as well as VA personnel and veterans organizations in the community

# One Program

- Iowa City VAMC presented to Family Readiness Groups (FRGs) about VA eligibility and services
- Assumptions regarding family outreach
  - Recognize reintegration concerns more quickly
  - Patient advocates (at home and in the clinic)
  - Better at “catching” the information

# Learning from Family Members

- Parents and spouses receive/filter the information differently
  - Spouse message: VA does not provide services for our family.
  - Parent message: The VA provides a lot of services you can use. Take advantage of them.
- Families have established informal networks and points of contact they engage to find out information

# Patient Involvement

- Benefits: Patients can be conduits of clinical practice guidelines
- Concerns: Are patients comfortable with this role? Do they need to be informed of the role?
- Critical Issue: Were patients activated to engage in their health care or did they feel obligated to participate in research?

# Caregiver Involvement

- Benefits: Personal, in-depth, temporal perspective of the health and well-being of the patient
- Concerns: Does research with caregivers diminish trust with patient?
- Critical Issue: Human subjects and PHI