Healthcare Survival Skills
An occupational therapist-disability peer led intervention – feasibility, acceptability and preliminary outcomes

Susan Magasi, PhD
Laura VanPuyymbrouck, PhD, OTR/L

Program for Healthcare Justice for People with Disabilities
Basic Assumptions

• ‘Without health nothing else is possible.””
  • Tom Shakespeare

• Health and healthcare are basic human rights.

• A baseline of health is foundational to occupational engagement and participation.

• People with disabilities are an unrecognized health disparities population.

• Negotiating the healthcare system is a hidden occupation and vital IADL.
Limitation of Focus of Rehab and a Potential Opportunity

- Healthcare management is part of OT’s scope of practice.
- Strategies related to the occupation of healthcare management are rarely addressed.
- Limits of professional knowledge.
- People with disabilities have rich experiential knowledge.
- This knowledge is not systematized or routinely shared.
Healthcare Survival Skills – An OT-Peer Led Intervention
Provider-Peer Led Approach

• Peer educator
  – Growing body of evidence around use of peer support interventions

• Occupational therapy
  – skills in activity analysis, self-advocacy strategies, pathways for accommodations specific to well-being, health management and health maintenance

• Study innovation – pairing strengths from both to address healthcare access for PWD

• Emphasis on occupation (the doing) of healthcare management
Intervention Overview
Intervention Overview

Delivery format
  OT-Disability Peer Led manualized “educational” intervention to build knowledge and skills

Learning Strategies
  Experiential, transformational and social learning

Dosage
  Plan
    Frequency – weekly
    Duration – 5 weeks, 90 minutes per session

  Reality
    Frequency – weekly
    Duration – 2 weeks, 2 ½ hour per session

Follow Up
  1 week, 6 weeks post
Pilot Feasibility Sample

2 groups

N = 9

Cross disability sample, incl. people with SCI, stroke, complex medical issues ➔ ↓ functional mobility.

Gender – 6 male, 3 female

Race – 8 African American, 1 white
Results - Feasibility

• Recruitment challenges
• Siting of groups (where to host)
• Structural and scheduling changes
  – Changed from 5 sessions to 2 longer days
  – Transportation barriers
• Fidelity
  – Higher for disability peer than for OT
  – Complexity of disability peer’s experience made participation a challenge.
  – Use of multiple peers.
Results
Preliminary Outcomes

↑ Knowledge of ADA

↑ Knowledge of rights in healthcare setting

↑ Understanding of approaches to self-advocacy

↑ Patient activation (measure of self-efficacy in healthcare setting and self-management)
Results - Acceptability

Emphasis on Occupation of Health Management

“I think it’s a good program...there’s a lot of programs I’ve been involved in that just [talk]...this is something that you’re giving back to us as a handicapped [sic] group...I mean you’re an occupational therapy group...we didn’t lift anything, we didn’t walk, we studied things to behoove ourselves in our recovery and I thank you for that”
Results - Acceptability

Transformational Learning (reframing experiences)

“Made me think about things in a new way.”

“Knowing rights was helpful. I didn’t know we had rights to all that (like in the hospital), that was new to me...I didn’t know we had rights to say anything to doctors, but now I know.”
Results - Acceptability

Emphasis on Empowerment

“Everything made me think of things in a more empowered fashion. That a lot of times individuals, it seems like you’re the handicapped [sic] guy and you just need to sit in the corner. But speak up for yourself, and you show that by doing that...you can feel like you’re a 100% fit individual even though you have a disability.”
Results - Acceptability

Opportunities for Improvement
“Goals were hard to follow. Following through on the goals was going to be hard.”

“It’s a lot to remember.”

“When I’m in the class, I’m focusing on the director (teacher). The other guy distracted me ... I did not like when other participant gave advice.”

Provision of more resources and links to direct services.
Next Steps

Looking for others to test intervention in diverse clinical populations.

Contact
Susan Magasi
smagas1@uic.edu
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Collaborators
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Sherry Muir, PhD, OTR/L, St. Louis University
Denise Nepveux, PhD, OTR/L, Utica College
Jessica Weiler, OTR/L, UIC