

The Experience of Nine Stakeholders Through the Lens of Actor-Network Theory

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Background: Neurogenic Bladder & Intermittent Catheterization 101

- Neurogenic bladder (NB)
 - Often occurs in conditions like spinal cord injury, spinal bifida, & multiple sclerosis
 - Bladder can't empty; individual needs to insert a catheter to drain urine
 - Not optional, can't wait. If it doesn't happen, infection and/or serious illness follows

Catheterization

- Life-saving technique, practiced for millennia (noted in ancient Egyptian papyri)
- Two basic types: indwelling (catheter stays in); intermittent (catheter inserted periodically)
- Fewer infections associated with intermittent (IC)
- People with neurogenic bladder (NB) preferentially get IC
- IC have evolved as a consumer product, wide variety of features (ex. "coated" or "hydrophilic") and corresponding price points
- Insurers apply strict "medical necessity" criteria to determine who gets which IC systems
 - ➤ Nuanced, quality-of-life factors don't automatically enter into reimbursement policy

Research Questions

- What are the patterns of *resourcing* that people with NB use to get their ICs?
- What inhibitors and enablers do they encounter?

IMPORTANCE

- Which IC technologies are paid for and by whom, influences the decisions people with NB make around how they manage their bladders
- How they are able to manage their bladders, in turn, drives people's decision making relative to life goals and how they will participate in society.

Quick Illustration: Typical Female Toileting

- ICs come in closed (bag, \$\$) and open/straight (tube, \$) varieties
- The bar is higher (demonstrating necessity with multiple urinary tract infections or other pathology) for getting closed systems, regardless of life factors (for instance, just being female)

"Men can urinate into a urinal. Women have to go into the stall. It doesn't matter if they washed their hands before they got onto the toilet, they have touched everything in the place. So by giving them closed bags it — even if they have to go into a stall -- it just eliminates a lot of the germs." (Fran)

"So, where I usually can cath from my chair with the bag, with these (lower end) catheters that I get from the medical supply store, I have to transfer to the toilet and cath into the toilet --which at home is fine, but sometimes out in public, it's not feasible. So I do plan. Ok, if I'm going to go somewhere, can I access the bathroom because of this straight cath? Otherwise, with the closed system, if I can get into a private space with a closed door, then I can go ahead and do what I need to do." (Amy)

Authors' Perspectives

Research

- Technology use to restore/promote function in disability
- Bladder management field research

Medicine

- Spinal cord injury medicine
- Community health and wellness

Policy

- Disability-competent care
- Patient- (Health Consumer-) centered care

Advocacy

• 2 authors are people with NB (post spinal cord injury)

PCORI

- Project supported by PCORI, Patient-Centered Outcomes Research Institute
- grant number: PCORI/AD-1310-08215: The impact of self-management with probiotics on urinary symptoms and the urine microbiome in individuals with spinal cord injury (SCI) and spina bifida (SB).

United by:

A deep concern for optimizing the wellbeing of and opportunities available to people with NB.

The desire to get high-level insight into how resourcing took place, who was involved, and how strategies modulated in response to changing circumstances.

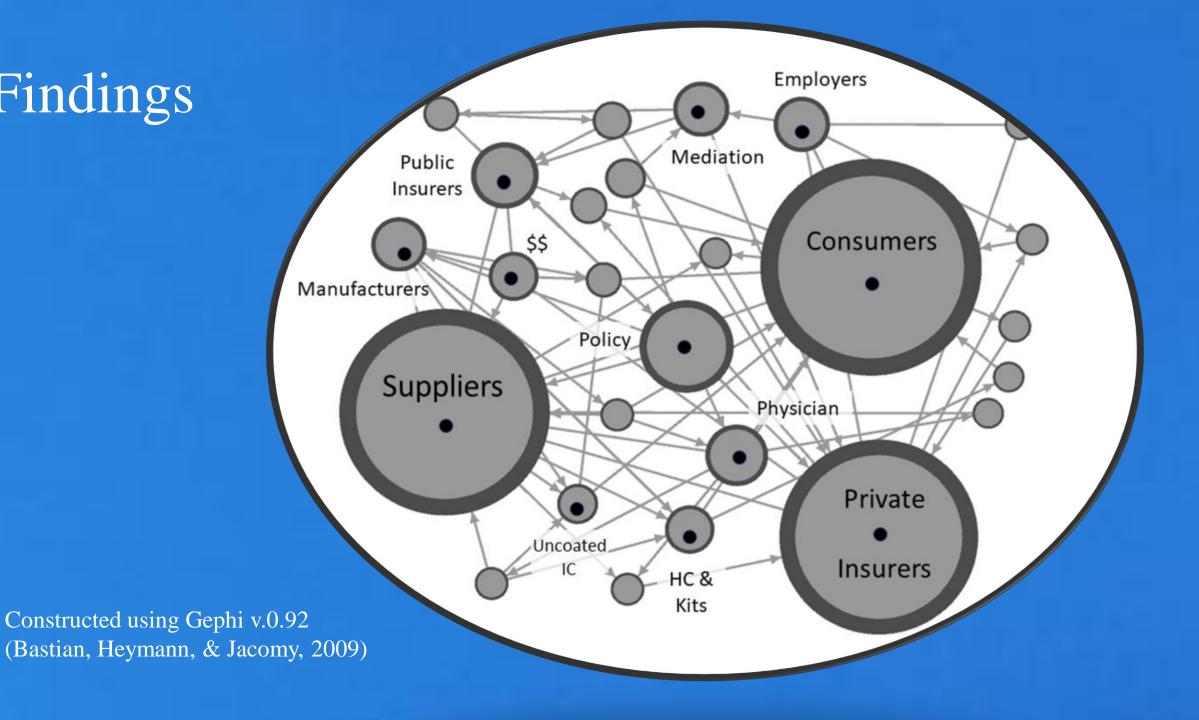
Methodology

- Actor-Network Theory (ANT)
 - Conceptual framework
 - ANT considers "actors," both human and non-human, and how they exert influence, creating push and pull, in the networks in which they act.
 - People, things, abstractions, all have the potential to exert influence
 - Used to explore the interplay of persons organizations, policies and technologies that make up the IC reimbursement ecosystem in the US

ANT Phases

Phase	Description
I. Identify the stakeholders	Identify the human (people, capable of volitional acts) and non-human (ex rules, technologies, money) actants who influence or are influenced by one another in catheter reimbursement.
II. Investigate the stakeholders	Examine the experiences and perspectives of human stakeholders through interviews and reviews of the documents they provide.
III. Identify stakeholder interactions	Trace interactions among stakeholders to explore how they influence one another.
IV. Construct an actor-network model	Visualize such aspects of the network as convergence and distribution.
V. Identify inhibitors and enablers	Determine who/what enables and inhibits actions in the network.
VI. Examine irreversibility	Determine to what degree it would be difficult to make a change.

Findings



Inhibitors

- Inhibitor 1. Paucity of reimbursement codes, failure to differentiate HCs (hydrophilic) from uncoated ICs
- Inhibitor 2. Opacity of private insurance
- Inhibitor 3. Need to document recurring UTI to be eligible for hydrophilic and closed catheters
- Inhibitor 4. 200 catheter per month cap
- Inhibitor 5. Lack of discernment among consumers relative to catheters

Enablers

- Enabler 1. Negotiability of private insurance plans between insurers and corporate purchasers
- Enabler 2. IC variety
- Enabler 3. OTC (off the shelf) availability of basic straight catheters
- Enabler 4. Centrality of the supplier

Discussion

- Meaning for Health of People with NB
 - Need for a proactive approach
 - Need for policy update
- Generalizability
 - Utility of Actor-Network Theory for understanding systemic relationships
 - Illustration of the mismatch between needs, services, and how they are provided in a network (here, medical equipment reimbursement)
 - Illustration of the role of information lag in informing policy

Q & A

• Thoughts, questions?

Selected References

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- See our paper in TQR for full reference set
 - Schladen, M. M., Rounds, A. K., McManus, T., Bennewith, A., Claypool, H., & Groah, S. L. (2021). Intermittent catheter reimbursement in the United States: The experience of nine stakeholders through the lens of actor-network theory. *The Qualitative Report*, 26(2), 443-464. https://doi.org/10.46743/2160-3715/2021.4660

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 - http://www.etennurologicalsupplies.com/Cure-Medical-Intermittent-Pediatric-Catheters-p/cmp8.htm