Patient’s Experience with Home Hemodialysis: A Qualitative Study

MASTER OF HEALTH SCIENCES IN COMMUNITY HEALTH

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March 6, 2015
Agenda

- Background
  - Statistics, Cost Analysis, Current Developments
- Purpose
- Gaps in Literature
- Theoretical Framework
- Methodology
  - Design, Interview Questions
- Results
  - Socio-Demographics, Emerging Themes
- Conclusion
→ HD remains the most prevalent type of dialysis in Canada, particularly at the in-centre locations at 79%  (Ontario Renal Network, 2011).
## Corporation Data

**Proportion of Prevalent Dialysis Patients by Treatment Type:**
(ORN, 2014)

<table>
<thead>
<tr>
<th>Type</th>
<th>Q2 FY 11/12</th>
<th>Q2 FY 14/15</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility-based HD</td>
<td>62.3%</td>
<td>71.2%</td>
<td>8.9%</td>
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<tr>
<td>Home HD</td>
<td>12%</td>
<td>10.3%</td>
<td>-1.7%</td>
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</tbody>
</table>
Costs Analysis
(McFarlane et al., 2002, 2003, 2011)

- All forms of dialysis are expensive
- In-centre costs $60,000-$95,000 annually per patient in North America
- HHD is more intense and frequent therapy, in-centre HD proves to be more costly.

- Staffing, overhead & support, admission, procedures
- Materials, lab tests, depreciation
Cost Analysis

- McFarlane, Pierratos and Redelmeier (2002) conducted a one-year descriptive costing study at two centres in Toronto, ON. Moving dialysis into the home can cut over $60,000 each year per patient. Considering there are over 23,000 patients receiving HD in Canada there is a significant monetary incentive to increase the uptake of independent dialysis and cost savings will be more marked over time.
“The choice of renal replacement modality is not simply a reflection of an individual’s psychosocial attributes, but rather a complex interplay between the patient’s health state and the perceived benefits and barriers to adopting the chosen therapy.” (Cefazzo et al., 2009)
Current Developments

- Provincial Leader for managing and delivering renal services

**Ontario Renal Plan**

- Reduce the burden of CKD, improve quality of care
- Recognizes an opportunity to enhance autonomy, quality of life, and outcomes for patients with CKD, while reducing costs to the overall healthcare system through increased uptake of independent dialysis (ORN, 2014)
Purpose

• Explore the experience of HHD patients and identify common benefits and barriers.

Research Question:
What are the common benefits and barriers that emerge through the exploration of the HHD patient experience?
Gaps in Literature

- No research on HHD in Durham Region (1st in Central East LHIN)
- Optimal strategy to teach and learn about NHHD has not been thoroughly assessed
- Patient preferred vascular access requires further clarification
- Understanding the patient’s dialysis experience through their own reflection (surveys, QoL tools)
- Although past research has linked HHD with improved quality of life and clinical outcomes they have not explored the patient experience using semi-structured interviews with open ended questions
- Lack of theoretical frameworks used to support research
The Theoretical Framework

The Health Belief Model (HBM)

- Developed in the 1950's
- Has been revised over the years
- Aimed at understanding and reducing barriers to a health related action

Consists of six fundamental constructs:

- Perceived Susceptibility - not susceptible
- Perceived Severity
- Perceived Benefits
- Perceived Barriers
- Cues to Action - all receive treatment
- Self-efficacy
Methodology

- 3 observation days at community-based hospital
- Recruited 20 patients on-site during clinic days

**Data Collection**
- Semi-structured interviews at LHW
- Consent, Nicknames, socio-demographic information
- 5 themed interview questions
- Audio recorded

**Data Analysis**
- Transcribed by principle investigator
- Template Approach (HBM constructs)
- Thematic Analysis (Nodes)
Themed Questions

1: Share with me how you came to start HHD therapy and your transition experience to home dialysis? Was there anything or anyone that had an influence in your decision?

2: What is it about this type of therapy that has a positive effect in your life? What do you like about it? What makes it easy?

3: What are the challenges you have found or continue to face with home therapy? What makes it hard?

4: Who or what helps you deal with the challenges? Do you rely on a caregiver? What could help you continue this home therapy?

5: In your opinion what could enhance your dialysis experience at home?
## Participant Socio-Demographics

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<thead>
<tr>
<th></th>
<th>Statistics</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td>13 males; 7 females</td>
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<tr>
<td><strong>Age</strong></td>
<td>Range: 31-85; Mean: 56; Median: 51</td>
</tr>
<tr>
<td><strong>Living Arrangement and Location</strong></td>
<td>20 house - 5 Whitby; 5 Oshawa; 2 Ajax; 1 Pickering; 1 Brooklin; 1 Courtice; 1 Bowmanville; 1 Newcastle; 1 Port Perry; 1 Little Britain; 1 Port Hope</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>15 married; 2 single; 1 divorced; 1 common law; 1 widowed</td>
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<tr>
<td><strong>Level of Education</strong></td>
<td>8 High School; 8 College; 4 University</td>
</tr>
<tr>
<td><strong>Annual Personal Income</strong></td>
<td>Range: $10,000 - $120,000; Mean: $44,300; Median: $30,500</td>
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<tr>
<td><strong>Annual Household Income Range</strong></td>
<td>Range: $16,000 - $250,000; Mean: $95,111; Median: $72,500</td>
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Emerging Themes

<table>
<thead>
<tr>
<th>HBM Constructs</th>
<th>Emerging Themes</th>
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<tbody>
<tr>
<td>Perceived Benefits</td>
<td>➢ Personalized and Flexible Treatment Schedule</td>
</tr>
<tr>
<td></td>
<td>➢ Autonomy and Psychological Benefits</td>
</tr>
<tr>
<td></td>
<td>➢ Physical Health Benefits</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>➢ Management of Supplies</td>
</tr>
<tr>
<td></td>
<td>➢ Self-Cannulation</td>
</tr>
<tr>
<td></td>
<td>➢ Travel Restrictions</td>
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<tr>
<td></td>
<td>➢ Troubleshooting Alarms</td>
</tr>
<tr>
<td>Perceived Severity</td>
<td>➢ Mindset</td>
</tr>
<tr>
<td></td>
<td>➢ Compulsory for Survival</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>➢ Confidence with Experience</td>
</tr>
<tr>
<td></td>
<td>➢ Caregiver Support</td>
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<tr>
<td></td>
<td>➢ Vascular Access</td>
</tr>
<tr>
<td>Perceived Benefits</td>
<td>Personalized and Flexible Treatment Schedule</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>----------------------------------------------</td>
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<tr>
<td></td>
<td>“There’s no schedule. It’s my schedule. I can do it as much as I want or as little as I want, if my needs change around my family”</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>Management of Supplies</td>
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<td>Mindset</td>
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<tr>
<td>Compulsory for Survival</td>
<td>“You can’t just pick up and go, so you are attached to your machine in a way for survival.”</td>
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<tr>
<td>Self-Efficacy</td>
<td>Confidence with Experience</td>
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<td>Caregiver Support</td>
<td>“…just having a person there to be with them all the time and giving them support when it is needed I think is a big advantage.”</td>
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<tr>
<td>Vascular Access</td>
<td>“I have a line [CVC] and I do everything on my own, totally independent.”</td>
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## Table 2

### Trustworthiness Criteria

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<thead>
<tr>
<th>Criteria</th>
<th>Definition</th>
<th>Techniques</th>
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<tbody>
<tr>
<td>Credibility</td>
<td>Confidence in the “truth” of the findings</td>
<td>-</td>
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<tr>
<td></td>
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<td>Prolonged engagement</td>
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<td></td>
<td></td>
<td>Persistent observation</td>
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<tr>
<td>Transferability</td>
<td>Showing that the findings have applicability in other contexts</td>
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<tr>
<td></td>
<td></td>
<td>Thick description</td>
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<tr>
<td>Dependability</td>
<td>Showing that the findings are consistent and could be repeated</td>
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<td></td>
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<td>External audits</td>
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<tr>
<td>Confirmability</td>
<td>A degree of neutrality or the extent to which the findings of a study are</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>shaped by the respondents and not researcher bias, motivation, or interest.</td>
<td>Audit trail</td>
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<td></td>
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<td>Reflectivity</td>
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Strengths

- **Open-ended questions** → although their responses may not have matched with the specific question asked, it brought their foremost thoughts to the surface.
- Findings did not emerge only at the last stages of research and the interview itself acted as an interactive learning tool.
- Adding **HBM constructs** demonstrates the genuine importance to comprehend the rich qualitative data.
- Interviewing twenty participants and reaching data saturation was a significant advantage and represented approximately **40% of HHD patients** at the community based hospital.
Limitations

- Non-randomization sampling method due to the nature of the dialysis cohort.
- If the HBM framework was not used results may have varied.
- Excluding patients lacking English literacy eliminated possible communications barriers.

Potential Bias

- **Response bias** - patients may not have been entirely truthful.
- **Instrument bias** - PI personally collected, analyzed and interpreted the data.
Research Implications

Theoretical Implications:
• Qualitative research seeks to understand meaning, and we investigate what it means to live as a HHD patient.
• 4 HBM constructs represent highlights (both negative and positive) as perceived by a HHD patient and together shape their lived experience.

Practical Implications:
• **ORN Priority** → enhance autonomy, quality of life, and improve uptake of independent dialysis.
  - Highlight benefits / Reduce barriers
• This research provides a foundation for developing practical solutions to retain HHD patients and improve their experience.
Future Research

**Education**
- Investigate the impact of current education programs, real-time access to training.

**Caregiver Support**
- Multiple caregivers, does in-home support allow more patients to adopt HHD?

**Health Benefits**
- Confirm physical health benefits associated with HHD.

**Water Treatment**
- Investigate the frequency and reoccurrence of plumbing issues and strategies for improving reliability.

**Electronic Data Sharing**
- Explore opportunities for an electronic tracking system. How might technology improve a patients experience?
“What I tell people it’s like brushing your teeth. It’s part of your routine you just do it”
References


Ontario Renal Network (2013). Proportion of incident hemodialysis patients by vascular access type and CKD regional program, Ontario, FY12/13. Retrieved from http://www.renalnetwork.on.ca/ontario_renal_plan/vascular_access/ckd_data/incidence_and_prevalence/#.VFkRg8m9bD1


Thank You!

time for questions

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