Engaging in a Meaningful Research Partnership: The Protective Community Residences Example

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The Partners

- Western Regional Health Authority
  - Kelli O’Brien - VP Long Term Care and Rural Health
  - Darlene Welsh – Regional Manager of Research and Evaluation
  - Trudy Read, Manager of the Protective Community Residences
  - Staff, Protective Community Residences

- Western Regional School of Nursing
  - Dr. Carla Wells – Research Coordinator/Nurse Educator
  - Judith Wells – Nurse Educator
  - Anna Marie Alteen – Nurse Educator

- Grenfell Campus of Memorial University
  - Dr. Les Cake – Honorary Research Professor, Psychology Department

- Community
  - Residents and families

- Others
  - CHSRF -EXTRA
Outline

• Engaging Partners in the Research Opportunity

• The Research and Outcomes

• Benefits

• Challenges

• Lessons Learned

• Discussion/questions
Engaging Partners in the Research Opportunity

EXTRA Fellowship

*Protective Community Residences = Intervention Project:*

Develop and introduce an alternate housing and support model for individuals with mild to moderate dementia based on best practices.
Western Health develops and introduces an alternate care environment for individuals with mild to moderate dementia and contributes to provincial direction for future dementia care.

**GOALS**
- Develop and Introduce an Alternate Care Environment for Individuals with Mild to Moderate Dementia
- Best Practice environment for dementia care
- Quality of Life

**INPUTS**
- WH Leadership & Commitment
- Provincial Direction: *Healthy Aging Policy Framework*  
  *Capital funding*  
  *Long Term Care & Supportive Services Strategy*
- Best Practices Review Committee
- Long Term Care Action Committee
- Dementia Care Review
- EXTRA and mentorship

**ACTIVITIES**
- Develop Strategic Partnerships
- Construction of bungalows
- Operational Plan-including building of human resource capacity
- Provincial Standards of Operation
- Promote New Model
- Conduct Evaluation/Research
- Link to Provincial Direction

**OUTPUTS**
- Construction of Four Bungalows
- Service delivery model in place
- Criteria for admission and discharge
- Application and Screening Tools
- Relocation of eligible LTC residents
- Staff Recruitment & Orientation
- Standards
- Communication Awareness Strategies
- Evaluation/Research

**OUTCOMES**
- Western Health develops and introduces an alternate care environment for individuals with mild to moderate dementia and contributes to provincial direction for future dementia care.
- Awareness and Support of Alternate Model Amongst Providers, and Public
- Quality Care and Quality of Life
- Appropriate Care environment
- Safe relocation of appropriate residents from LTC environments
- Enhancing Research Partnerships
Engaging Partners in the Research Opportunity

- Email request to Grenfell to solicit interested faculty
- Expressed interest of committee members
- Invitation to partners who might be interested
- Engaging residents and their families
- Engaging staff
The Research

What was the family members’ perspective of the relocation experience?

- hermeneutic phenomenology qualitative methods
- Purposive sample of 10 family members

What was the impact of relocation on cognition, function, severity of dementia and behaviors of individuals with mild to moderate dementia.

- quantitative, descriptive study using pre and post measures
- Sample of convenience of first 41 residents to move into the PCRs
The Research

What were the care providers’ perspectives of the Protective Community Residences?

- Qualitative description
- Thematic analysis
- Focus group sessions with 15 staff
The Outcomes: Question 1

Six Key Themes:

- Ongoing Communication
- Relief and Contentment
- Meaningful Activities
- Enhanced Environment
- Improved Functioning
- Engaged Staff
The Outcomes: Question 1

- Implications
  - Some improvements needed within the bungalow
  - Ongoing resources allocated for recreation programs
  - Continued support from leadership
  - Ensure ongoing family involvement and open communication

- Key Message
  - Resident-centred care results in positive outcomes for residents and family members
The Outcomes - Question 2

Table 1 Demographics of Initial Residents Admitted to PCR 1-3 ($N = 41$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$N$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relocated from:</td>
<td></td>
</tr>
<tr>
<td>• Private Homes</td>
<td>15 (36.6)</td>
</tr>
<tr>
<td>• Personal Care Homes</td>
<td>7 (17.1)</td>
</tr>
<tr>
<td>• Acute Care</td>
<td>10 (24.4)</td>
</tr>
<tr>
<td>• Long Term Care</td>
<td>9 (21.9)</td>
</tr>
<tr>
<td>Current status as of September 2012</td>
<td></td>
</tr>
<tr>
<td>• Currently a resident of PCR</td>
<td>4 (10)</td>
</tr>
<tr>
<td>• Discharged still living</td>
<td>8 (20)</td>
</tr>
<tr>
<td>• Discharged but deceased post discharge</td>
<td>23 (55)</td>
</tr>
<tr>
<td>• Deceased as resident of PCR</td>
<td>6 (15)</td>
</tr>
</tbody>
</table>
### The Outcomes: Question 2

#### Table 2 Resident Functioning Pre and Post Relocation*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre Relocation $M(\text{SD})$</th>
<th>Post Relocation $M(\text{SD})$</th>
<th>$Z$ Score</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE</td>
<td>17.71(3.35)</td>
<td>16.57(4.56)</td>
<td>-1.336</td>
<td>0.18</td>
</tr>
<tr>
<td>GDS</td>
<td>3.37(0.62)</td>
<td>3.46(0.74)</td>
<td>-0.775</td>
<td>0.44</td>
</tr>
<tr>
<td>DAD</td>
<td>74.24(11.53)</td>
<td>77.79(21.09)</td>
<td>-1.501</td>
<td>0.13</td>
</tr>
</tbody>
</table>
Table 3 Neuropsychiatric Inventory Questionnaire Pre and Post Relocation ($N = 41$)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre N(%)</th>
<th>Post N(%)</th>
<th>Pre N(%)</th>
<th>Post N(%)</th>
<th>McNemar Test p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>11(28.2)</td>
<td>5(14.3)</td>
<td>28(71.8)</td>
<td>30(85.7)</td>
<td>N/S</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>6 (15)</td>
<td>5(14.3)</td>
<td>34(85)</td>
<td>30(85.7)</td>
<td>N/S</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>14(35)</td>
<td>10(28.6)</td>
<td>26(65)</td>
<td>25(71.4)</td>
<td>N/S</td>
</tr>
<tr>
<td>Depression/Dysphoria</td>
<td>10(25)</td>
<td>6(17.1)</td>
<td>30(75)</td>
<td>29(82.9)</td>
<td>N/S</td>
</tr>
<tr>
<td>Anxiety</td>
<td>8(20.5)</td>
<td>4(11.4)</td>
<td>31(79.5)</td>
<td>31(94.3)</td>
<td>N/S</td>
</tr>
<tr>
<td>Elation/Euphoria</td>
<td>0(0)</td>
<td>0(0)</td>
<td>40(100)</td>
<td>35(100)</td>
<td>N/S</td>
</tr>
<tr>
<td>Apathy/indifference</td>
<td>2(5)</td>
<td>2(5.7)</td>
<td>38(95)</td>
<td>33(94.3)</td>
<td>N/S</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>2(5)</td>
<td>2(5.7)</td>
<td>38(95)</td>
<td>33(94.3)</td>
<td>N/S</td>
</tr>
<tr>
<td>Irritability/Lability</td>
<td>9(22.5)</td>
<td>5(14.3)</td>
<td>31(77.5)</td>
<td>30(85.7)</td>
<td>N/S</td>
</tr>
<tr>
<td>Motor Disturbance</td>
<td>3(7.5)</td>
<td>4(11.4)</td>
<td>37(92.5)</td>
<td>31(88.6)</td>
<td>N/S</td>
</tr>
<tr>
<td>Nighttime Behaviors</td>
<td>4(10)</td>
<td>3(8.6)</td>
<td>36(90)</td>
<td>32(91.4)</td>
<td>N/S</td>
</tr>
<tr>
<td>Appetite/Eating</td>
<td>3(7.7)</td>
<td>1(2.9)</td>
<td>36(92.3)</td>
<td>33(97.1)</td>
<td>N/S</td>
</tr>
</tbody>
</table>
The Outcomes: Question 3

Satisfaction of the care providers was found to fall into eight main themes:

- Orientation
- Quality of Care
- Physical Environment
- Resident Safety
- Staff Safety
- Placement Appropriateness
- Support
- Job Satisfaction
Benefits of Using a Collaborative Approach

- Research questions - relevant to all partners

- Research design-skills acquisition, improved quality of data
  - Building internal capacity within health system

- Data analysis and interpretation-skills acquisition

- Contextual factors considered- therefore improved relevance and acceptance of conclusions
Benefits of Using a Collaborative Approach

• Division of labour

• Team skill mix
  • Partnerships facilitate having the right expertise around the table
  • Appropriate health system decision maker involvement/leadership

• Established partnerships can facilitate future projects
  • HARP research grant and working group for Centre on Aging
Benefits of Using a Collaborative Approach

- Dissemination of results—broader distribution—multiple conferences both research and leadership focus, and publications.


Question 3. Repeat testing (post-test) and publication planned.
Challenges of Using a Collaborative Approach

- Cultural differences between academia and other organizations
  - Historical lack of incentives – promotion and tenure expectations

- Practical, operational barriers
  - Research funding
  - Ethical approval process more rigorous with vulnerable populations
  - Investment to develop relationships
Challenges of Using a Collaborative Approach

- Practical, operational barriers (cont’d)
  - Timelines, schedules, and competing priorities become complicated when dealing with multiple partners
  - Reliance on others to complete their tasks in a timely fashion

- Defining accountabilities
  - Needs to be clear upfront
  - Frameworks exist around collaborative research that can be used (for eg. CHSRF)
Lessons Learned

- Knowledge of all elements of ethics
- Need to have the right skill mix on the research team
- Need for decision makers to be part of the research team to facilitate the implementation of recommendations
- Close geographic proximity facilitated the progression of our work
“People acknowledge that when they are involved in making decisions affecting their future, they develop a sense of ownership and commitment to carrying out those decisions”

-John Burbridge, Beyond Prince and Merchant
Conclusion

This case study illustrates how local partners, including community, were effectively engaged in a meaningful research project.
Discussion & Questions