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

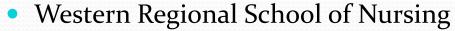
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 - Kelli O'Brien VP Long Term Care and Rural Health
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 - Staff, Protective Community Residences



- Dr. Carla Wells Research Coordinator/Nurse Educator
- Judith Wells Nurse Educator
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- 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- Protective Community Residences Project

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

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ACTIVITIES

OUTPUTS

OUTCOMES

WH Leadership & Commitment

Provincial Direction:

Strategy

* Healthy Aging Policy Framework * Capital funding * Long Term Care & Supportive Services

Best Practices Review Committee

Long Term Care Action Committee Dementia Care Review

EXTRA and mentorship

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

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 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



Six Key Themes:

- Ongoing Communication
- Relief and Contentment
- Meaningful Activities
- Enhanced Environment
- Improved Functioning
- Engaged Staff

- 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

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

Variable	N(%)
Relocated from:	
• Private Homes	15(36.6)
• Personal Care Homes	7(17.1)
• Acute Care	10(24.4)
• Long Term Care	9(21.9)
Current status as of September 2012	
• Currently a resident of PCR	4(10)
• Discharged still living	8 (20)
Discharged but deceased post discharge	23 (55)
• Deceased as resident of PCR	6 (15)

Table 2 Resident Functioning Pre and Post Relocation*

Variable	Pre Relocation M(SD)	Post Relocation M(SD)	z on Score	P	
MMSE	17.71(3.35)	16.57(4.56)	-1.336	0.18	
GDS	3.37(0.62)	3.46(0.74)	-0.775	0.44	
DAD	74.24(11.53)	77.79(21.09)	-1.501	0.13	

Table 3 Neuropsychiatric Inventory Questionnaire Pre and Post Relocation $(N = 41)^*$

					McNemai Test
Variable	Pre	Post	Pre	Post	
	N(%)	N(%)	N(%)	N(%)	р
	YES		No		
Delusions	11(28.2)	5(14.3)	28(71.8)	30(85.7)	N/S
Hallucinations	6 (15)	5(14.3)	34(85)	30(85.7)	N/S
Agitation/Aggression	14(35)	10(28.6)	26(65)	25(71.4)	N/s
Depression/Dysphoria	10(25)	6(17.1)	30(75)	29(82.9)	N/S
Anxiety	8(20.5)	4(11.4)	31(79.5)	31(94.3)	N/S
Elation/Euphoria	0(0)	0(0)	40(100)	35(100)	N/S
Apathy/indifference	2(5)	2(5.7)	38(95)	33(94.3)	N/S
Disinhibition	2(5)	2(5.7)	38(95)	33(94.3)	N/S
Irritability/Lability	9(22.5)	5(14.3)	31(77.5)	30(85.7)	N/S
Motor Disturbance	3(7.5)	4(11.4)	37(92.5)	31(88.6)	N/S
Nighttime Behaviors	4(10)	3(8.6)	36(90)	32(91.4)	N/S
Appetite/Eating	3(7.7)	1(2.9)	36(92.3)	33(97.1)	N/S

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 distributionmultiple conferences both research and leadership focus, and publications.

Question 1. Hutchings, D., Wells, J.L., O'Brien, K., Wells, C., Alteen, A.M. and Cake, L.J. (2011). From Institution to "Home": Family perspective on a unique relocation process. Canadian Journal on Aging 30(02): 223-232.

http://dx.doi.org/10.1017/S0714980811000043

Question 2. Manuscript submitted to Perspectives: Canadian Journal of Gerontological Nursing April 2013.

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.



Care and Support Team • PCR Planning Team
Assessment and Placement Team • LTC Redevelopment Team
Evaluation Team

Discussion & Questions



