

Building Research Capacity to Examine Nursing Home Resident and Family Quality of Life

Workshop Report

July, 2009

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Workshop Overview

Workshop on Building Research Capacity to Examine Nursing Home Resident and Family Quality of Life was held June 18, 2009 at Mount Saint Vincent University, in Halifax, Nova Scotia.

The workshop was organized by Dr. Janice Keefe, Director, Nova Scotia Centre on Aging (NSCA) and Dr. Robin Stadnyk, School of Occupational Therapy, Dalhousie University, and was made possible by financial assistance received from the Centre for Interdisciplinary Research on Human Development, Mount Saint Vincent University. The specific focus of the workshop was to build research capacity to examine the impact of developments on quality of life for nursing home residents and their families. The objectives were to:

- Identify potential topics/areas of interest for a funding proposal(s).
- Identify a potential team for a funding proposal(s).
- Identify a framework and protocols for a funding proposal(s).

Participants collaborated to achieve these goals, and took part in group discussions to identify broad topics of interest. They then separated into small working groups, and brainstormed potential research areas related to each topic. Topics were further narrowed, and two priority topics were identified for discussion in great depth (see Appendix A for Workshop Agenda).

Fifteen individuals attended the workshop (see Appendix B). Participants included researchers from a variety of disciplines (e.g., occupational therapy, social work, nursing) as well as decision makers and practitioners. Most individuals were from Nova Scotia, with the exception of one participant who was from Prince Edward Island, one from New Brunswick, and one who was currently completing her Master's degree in British Columbia (Simon Fraser University). A number of other individuals expressed interest in the workshop and its objectives but were unable to attend. Evaluation results (Appendix C) indicate the workshop experience was positive.

Dr. Janice Keefe and Dr. Robin Stadnyk facilitated the day. NSCA staff – Pamela Fancey, Brenda Hattie and Emily White – assisted with event planning and facilitation.

Context for Workshop

The NS Department of Health is moving forward with its plans to increase long term care bed capacity in the province. Part of this development includes attention to physical design and staffing responsibilities for facilities approved for the new beds. One of the approved facilities is Northwoodcare Inc. in Halifax, which is scheduled to open its new facility in the spring of 2010. Their 150-bed facility contains a new floor plan that features the “neighborhood design” (i.e., small self contained units of 10-12 residents) and staffing organized on resident relationships, as opposed to hierarchical relationships. Each of these innovations has the potential to enhance the experiences of staff, residents and their families.

In May 2008, Northwood hosted a “research day” inviting researchers and decision makers to help build a program of research and to identify potential areas for collaboration. One of several areas of inquiry identified during that day was in what ways the new developments will impact the resident and his/her family. Dr. Janice Keefe, Director, Nova Scotia Centre on Aging, and Dr. Robin Stadnyk, School of Occupational Therapy, Dalhousie University obtained funding from MSVU to facilitate research in this area. Specifically, the immediate research funds were intended to foster and build an interdisciplinary research collaboration of academic researchers, practitioners and decision makers interested in examining resident quality of life and family involvement in long term care facilities. This was achieved through identifying individuals with expertise and interest; synthesizing existing knowledge; identifying potential funding sources; and hosting a workshop with interested researchers, practitioners, and decision makers.

In June 2009, invitations to participate in the workshop were extended to those thought to be interested in moving forward with an examination of how current changes in physical design and approach to care are affecting residents and their families. Efforts were made to include individuals from a range of areas, including those working in organizations, such as the Department of Health and the Nova Scotia Association of Health Organizations (NSAHO); academic researchers in the areas of occupational therapy, geriatric medicine, psychology, psychiatry, gerontology, health and human performance, physiotherapy, family and nutritional sciences, and nursing; as well as practitioners currently involved with long-term care facilities in a number of capacities.

Participants were provided with a background paper in advance¹. The aim of this paper was to familiarize individuals with the latest trends in approach to care and physical design; present measures commonly used to assess quality of life, quality of care, and resident satisfaction; synthesize the current literature addressing how such changes impact residents and their families; and finally, to highlight areas where further research is needed. The latter section provided a starting point for discussion at the workshop.

¹ Janice Keefe, Robin Stadnyk, Emily White, Pamela Fancey, “Building Research Capacity for Examining the Impact of Developments on Quality of Life for Nursing Home Residents and their Families: Background Document”, Nova Scotia Centre on Aging, Mount Saint Vincent University, Halifax, NS, June, 2009.

Workshop Highlights

This section outlines the workshop proceedings in brief and highlights the key points addressed.

Welcome & Context for the Day

The workshop began with an introduction to members of the research team, and a brief overview of the workshop framework, intended objectives, and expected outcomes. Ann McInnis, Vice-President of Community & Continuing Care at Northwood, then delivered a presentation to orient participants to Northwood's continuum of care, existing facilities and client services, and new Bedford West facility currently in development.

This new facility will espouse a different model of care, as the aim is to create a less institutionalized, and more "home-like" environment. Residents will experience greater choice and control, while living in clusters of 12 private rooms with washrooms (rooms are 190 sq ft, washrooms are 40 sq ft). Rooms for couples and obese individuals will also be available. Provisions have been made so each room has its own entrance and "porch" area. Each "neighbourhood" will consist of two clusters, and all will have open access to a dining room, kitchen, living area, and an outdoor courtyard which will include a children's playground. A salon, but no fitness centre, will be on site, and Bedford West will also have an Adult Day Centre. Community access will be open to this when it is not in use. Northwood will continue to operate its Halifax facility which has a traditional physical plant, but an active community life.

Issues associated with building the new facility were raised. One such concern was smoking, as how the facility plans to accommodate residents who smoke and the impact of this on staff has not yet been determined. Another potential concern is related to private rooms, and the impact on residents' quality of life. Private rooms may negatively impact residents' levels of social engagement, and may cause individuals to experience social isolation. There are also concerns regarding how to involve families, and how to engage the surrounding community, as Bedford West is located in a more suburban location as compared to the downtown Gottingen facility. There are also concerns about how this change will impact residents' sexual activity.

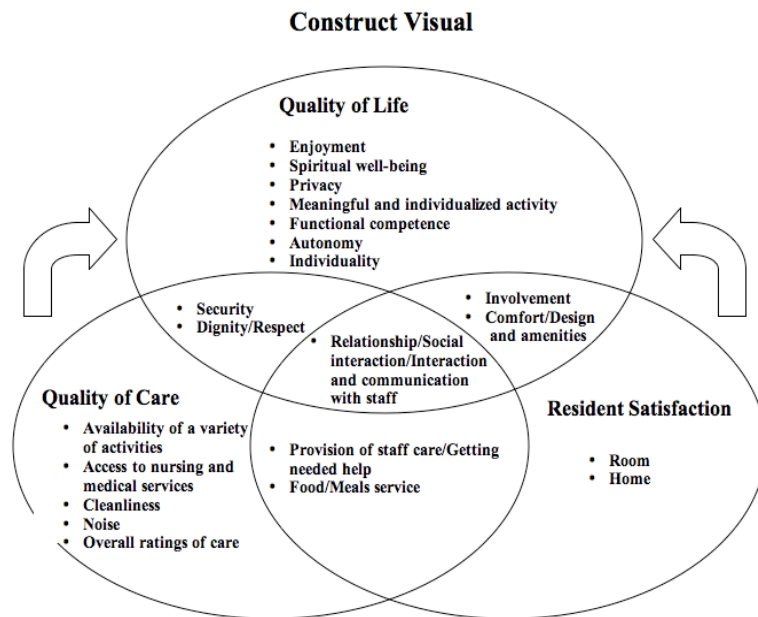
What we Know

Emily White, Research Assistant, NSCA, gave a presentation highlighting key points as described in the background document.

What We Learned

Overall, current approaches to care are now reflecting resident-centred perspectives, and resident choice, autonomy, and dignity are increasingly being emphasized. Changes in the physical design of long-term care facilities can also be seen, as homes are moving toward the neighbourhood design, also known as clusters, pods, or villages. With this shift in focus has come an increased demand for accountability. Researchers and

practitioners alike are interested in the impact of such large-scale changes. In looking into this literature, three main constructs to measure/understand change appear to be present: quality of life, quality of care, and resident satisfaction. Quality of life is a subjective concept, and relates to psychosocial domains, such as residents' perceptions and feelings. Quality of care has subjective components as well, but also includes service- or facility-related dimensions, such as nursing services. Finally, resident satisfaction appears to demonstrate elements of both quality of life and quality of care, and to an equal extent.



Impact of Changes in Approach to Care on Resident Quality of Life

Research addressing the impact of changes in approach to care on resident quality of life appears to have approached this through two main lenses: staff and family councils. Residents on units with more committed certified nursing assistants demonstrate higher quality of life, and satisfaction with staff care has been found to influence all other aspects of resident satisfaction. Relationships between family councils and higher resident quality of life have also been found, as such councils allow residents to be involved in centre-level decision-making, to provide input, and communicate concerns. This improves their feelings of self-worth and empowerment.

Impact of Changes in Physical Design on Resident Quality of Life

To a large extent, literature addressing how changes in physical design affect resident quality of life has focused on private rooms, and has found a number of associated positive results. The fact that residents can personalize their spaces is empowering to them, and having a space that is their own has a positive impact on feelings of privacy and control.

Impact of Changes in Approach to Care on Family Involvement

Research assessing the effect of changes in approach to care on family involvement has primarily focused on how such changes affect family visit frequency. Research has found that families perceive these new environments to be more conducive to visiting. Other studies have approached this area by exploring the impact of interventions specifically aimed at facilitating family involvement. Such initiatives aim to improve family members' understandings of life in the nursing home, encourage their input, and promote family-staff relationship formation. Such initiatives have been found to facilitate a common understanding between the two parties, open the lines of communication, and establish trust, openness, and recognition.

Impact of Changes in Physical Design on Family Involvement

The impact of changes in physical design on family involvement is an area that has been largely ignored. Initial results, however, are encouraging. Visitors, as well as residents, appreciate the increased privacy associated with the new design, as they help to facilitate more meaningful visits. Families are no longer forced to feel like unwilling observers of roommate's visits, and it has been observed that more family visit, stay longer, and use the space more freely.

Key Gaps

A Canadian perspective that incorporates our distinct context is lacking. Research that taps into residents' perceptions of how changes in approach to care impact their quality of life would also be beneficial, as much has looked at other factors, such as the impact of staff and family councils. Families' perspectives would also serve to more fully develop this picture. We must determine what changes in approach to care mean to them, and how they are affected by changes in physical design and space utilization. Finally, aspects associated with physical design must be further explored. To date, the literature has largely focused on private rooms. The large neighbourhood configuration must also be addressed.

Discussion Regarding the Literature

Following the presentation, participants were invited to make comments and ask questions, and a number of important issues were raised. Families, in particular, emerged as a central theme. Individuals noted families' concerns with residents having too much freedom, as this increases risk exposure. They also discussed the importance of supporting and educating families about how their roles and responsibilities will change and evolve post-admittance, and the ways in which they can foster resident autonomy, especially as many families are unaware of what the new model of long term care entails. Others mentioned the lack of literature surrounding the influence of environment on family involvement, although one individual noted that work by Morgan and Stewart examines this issue in relation to special care units. Other points raised centered on physical design, including the implications associated with single versus double rooms, the issue of person-environment fit, and social connectedness. How couples could be accommodated in private rooms was also raised.

Identifying Research Opportunities/Areas of Interest

Based on what learned from the literature and the opportunity being presented, a large group brainstorming session took place where participants were asked to think of potential research areas. From these discussions, five broad topics emerged:

- approach to care
- social isolation
- physical design
- transition to a new model
- policy interface

In groups of three, participants rotated around “gallery style” to each station. The goal of this exercise was to have them expand on and add new insights or information to each existing topic (see Appendix D). Broadly, approach to care included questions relating to what this new approach will include, and how it will affect residents, their families, and staff. Social isolation referred to the sources of isolation, and ways in which these challenges can be ameliorated. Physical design questions centered on space utilization by residents and visitors, and the impact of these new configurations on the social aspects of residents' lives. Topics included within transition to a new model focused on a desire to learn more about the transition experience and process, so successful transitions may be facilitated for residents, and formal and informal caregivers. Finally, policy interface referred to how existing policies affect facility operations, and ways of informing policy makers in order to move existing policies forward.

Understanding our Research Capacity

In this segment, participants were asked to note the specific interests, experience, and skills that they could bring to the research, so an understanding of the existing research capacity could be garnered. A wide range of experience and research interests were presented. The two primary areas concerned policy and family. Individuals expressed interest in how policy influences residents' lives, and specifically, how it can enhance and restrict quality of life. In terms of family, individuals communicated a desire to learn about how family caregiving is encouraged and discouraged in long term care facilities, how design affects them, and more about the needs of this group. Other areas of interest centered on residents' intimate relations, social isolation and support, the impact of physical design changes in new facilities, program evaluation, person-environment fit, transition within an existing or to a new facility, coping and adaptation, and palliative care within long term care. Participants also brought a variety of skill. Two expressed competence in quantitative research methods, two in qualitative, and four in mixed methodology. Three could contribute their expertise in research design and methods. Experience with measurement, assessment, and health measures was also noted. Three mentioned having access to graduate students who could help with literature search and review work, and as a number of participants had been previously or were currently employed with a long term care facility, they noted having access to potential participants, including residents and families. No participants have held or currently hold funding specific to this topic.

Building the Projects

From the research areas/topics identified, two main topics were selected by participants – physical design and transition to a new model – for further discussion about project development. It should be noted that many possibilities emerged during the discussion of the topics and participants were encouraged to discuss them further, but in the interest of time and achieving the workshop objectives, two ideas were selected. The two groups worked to compose research questions, develop appropriate design and methodology, identify funding opportunities, and to consider their own role in the project. During this time, individuals had access to a document outlining potential funding opportunities, and to an instrument binder that contained a number of tools commonly used to assess resident quality of life, quality of care, and satisfaction.

Discussion Group 1: Physical Design

Individuals working on this project idea began with a more general discussion of physical design in long term care facilities, and then focused on how the new site –Bedford West - itself (or in comparison to other sites) might affect the residents and the family's Quality of Life (QOL) including mastery.

Research Question: What is the effect of physical design and context more generally on Resident's and Family's Quality of Life?

An important feature of the in depth discussion was detailed information about: a) accessing the new facility (placement process), b) the transition model, and c) changes in service availability. The key dependent variable was resident Quality of Life examined by measures such as Intimate expression, Responsive behaviours, Social interaction, Social networks, Health – physical/mental (cognitive, emotional, spiritual), Participation/engagement and Mastery/autonomy.

- a) For example, Issues related to placement were discussed - who decides, and how, which residents go to the Bedford West site versus those who remain in an existing facility? What factors influence this decision to move from family and resident's perspective? What are the decision making factors around placement for the system – e.g. the single entry model? What is the impact of persons waiting to transition to new model (from Northwood).
- b) The transition model and the time frame in which the transition will occur was also valuable information as it lead to a discussion of applying successes in transition in a process evaluation format. Significant discussion occurred around the comparison of pods within the facility and/or across time. For example, What makes certain pods more engaged/integrated than their neighbors? (one could control for dementia for example - two pods similar, two different, mixed); QOL measures (interactions) whether curtains open or not; configurations of chairs, wheel chairs
- c) In addition, participants also discussed issues surrounding how funding of a facility impacts the scope of available services realizing that while the new

facility (Bedford West has a unique and “positive” physical design, the funding does not allow for the same level of support services (e.g. social worker). A comparison study was discussed: an old facility with services; a new facility without services compared to a new facility which never had services.

The practicalities of a study with multiple sites and services may be difficult to execute due to the associated methodological challenges (there are many variables that may distinguish these facilities; focusing only on physical design of the difference is a potential problem. Participants believed that examining different types of care settings within a facility may be doable, given that the approach to care and physical design will be consistent. There was interest in exploring whether residents in certain pods would demonstrate higher engagement than individuals living in others. As well, the segregated versus integrated pods with people with dementia would be of interest.

Potential funding sources included the Alzheimer Society of Canada for studies looking at the impact of integrated versus segregated sites, a Canadian Institute of Health Research (CIHR) Catalyst Grant, or funding through a Dalhousie University Foundation grant. The Nova Scotia Health Research Foundation (NSHRF) Community Research Alliance Grant was also noted; however, a team building grant may need to be obtained before applying for this.

Discussion Group 2: Transition to a New Model

Participants interested in topics related to transition to a new model spent the first portion of their discussion focused on the term "transition." There was significant discussion about what was meant by transition without any final consensus. As well, participants discussed what this new model would look like, and how it would differ between facilities. Specifically, they wanted to know how individuals would adjust to life in a new facility and what interventions may assist them to transition successfully. A number of group members also expressed interest in how staff is affected by transition to a new model. Potential research question included:

Research Question: What is the impact of the new model of care on residents and families?

Potential funding sources that were identified included the Drummond Foundation, and a NSHRF Community Alliance Grant. It was noted that funding for proposal development would first be needed in order to go forward with a larger project. Carole Estabrooks, Professor and Canada Research Chair in Knowledge Translation in the Faculty of Nursing at the University of Alberta, was also identified by one participant as a researcher who may be interested in becoming involved in such a project, as her research interests lie in the areas of organizational and health care outcomes.

Next Steps

The day concluded with a discussion about next steps/strategies to turn the fruitful discussion of the day into an application(s) for research funding especially given the time frame for the new Bedford West facility to be opened. Next steps include:

- identify a leader for proposed projects ideas and working collaboratively with those interested on an application
- select an appropriate funder
- identify a source of funding to support application development
- develop an application to support large collaborative proposal development

Project A - Segregation vs. Integration of persons with dementia - Does dementia advance, or plateau, because of living with others with dementia?

Potential funder - The Alzheimer Society of Canada. It was suggested development funds may be obtained from IA Catalyst Grant.

Lead and others interested - Janice Keefe agreed to take the lead on this application. Krista Frazee offered to contribute to the literature review and conceptual framework for the grant. Melissa Andrew is interested in the methodological approach to this study.

Project B – Compare and contrast models or care: the new environment/model, without support services (Bedford West); the old environment/model without support services (e.g. Tideview); and the old environment/model with support services (Northwood) in terms of the implications for residents, staff and families?

Potential funder – CIHR Partnerships in Health Systems Improvement. NSHRF Special Consideration Award may be obtained to support application development.

Lead and others interested – Judy Lowe agreed to take the lead on the SCA application. NSCA will help write the SCA application. Judy Lowe, representatives from Northwood and NSAHO offered to contribute – especially time and resources – to this project.

Project C – Examine implications of transition to new model of care.

Potential funder – not identified.

Lead and others interested – No Lead identified. Cheyenne Wyers offered to assist with grant development. Susan Doble expressed interest in the Transition project, but not in taking the lead on a proposal development.

Appendix A – Workshop Agenda

Workshop on Building Research Capacity to Examine Nursing Home Resident and Family Quality of Life²

Thursday, June 18, 2009

9:30 am – 4:00 pm

Room 401, Rosaria Student Centre (Don McNeil Room)

Mount Saint Vincent University

AGENDA

9:30 am	Welcome & Context for the Day
10:15 am	What we Know
10:45 am	Identifying Research Opportunities/Areas of Interest
11:30 am	Understanding our Research Capacity
12:30 pm	Lunch
1:00 pm	Choosing Priority Topics
1:30 pm	Building the Project(s)
2:45 pm	Report Back
3:15 pm	Next Steps
3:55 pm	Evaluation & Wrap Up

² This workshop has been made possible by financial assistance received from the Centre for Interdisciplinary Research on Human Development, Mount Saint Vincent University.

Appendix B - Workshop Participant List³

Melissa Andrew
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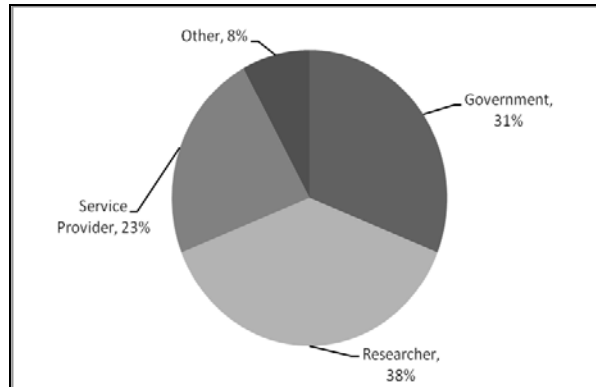
Cheyenne Wyers
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³ Names and contact information provided here with permission.

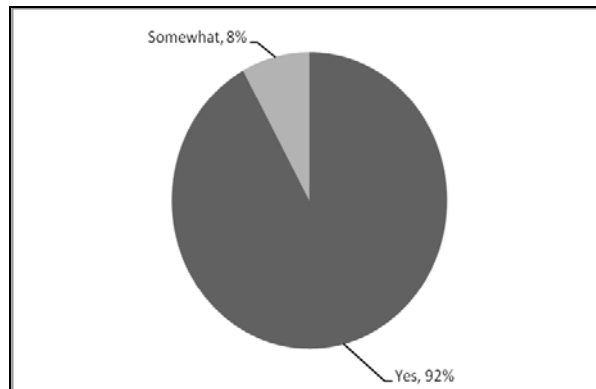
Appendix C – Workshop Evaluation Results

Total Participants: 15 Total Respondents: 13

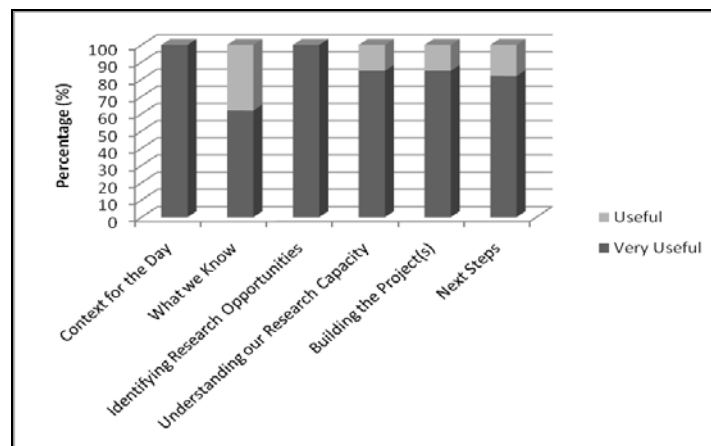
Participants' Background:



1. Was the background document helpful for orientation to the workshop?



2. Please indicate the usefulness of each Workshop segment.



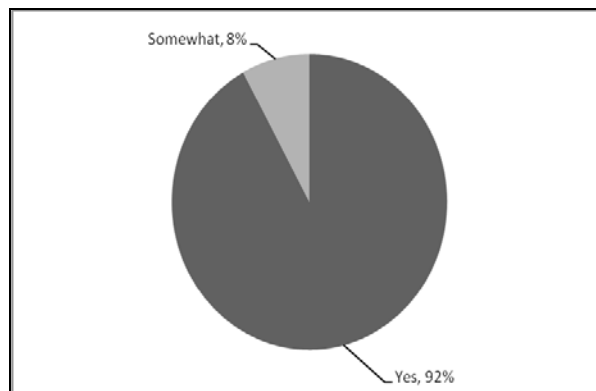
3. Were your expectations for the day met?

All respondents indicated “Yes”.

4. Did you have appropriate opportunities to contribute the ideas you consider important to the discussions?

All respondents indicated “Yes”.

5. Did the workshop provide an opportunity to network with others with similar interests?



6. What was the most valuable part of the workshop? Why?

Making connections with people with similar interests.

Networking.

Hearing about the possibilities and the interest.

Brainstorming research opportunities.

The sharing and discussions – very valuable.

Discussions and networking.

Identifying ideas for research projects; detailed planning of the two projects at the end;

Great to hear diverse input and ideas; very inspiring and exciting!

Generating the areas of interest and then from there generating research questions.

Variety – large group: small group and all of the prep documents.

Networking.

7. Other Comments:

[Note: blank spaces represent respondents who did not provide comments]

I'm still not sure if this project is specific to NS, or will be broader!

Thank you!

Thank you for the invitation!

Interesting workshop and opportunity for further research.

Thank you so much for helping us move our research agenda forward!

The organization for the day was excellent.

I thoroughly enjoyed the entire day, It presented me with an opportunity to wear my “research hat” that I don’t always have an opportunity to “wear.”
Would have perhaps been good to have identified (or secured commitment) for small amount of proposal development funding in advance.
Great day – good discussion!

Appendix D – Research Opportunities

Approach to Care	Social Isolation	Physical Design	Transition to a New Model	Policy Interface
<p>-Palliative care fit in new model</p> <p>-Admittance, placement to SCUs (how/ process?)</p> <p>-How integration affects new clusters</p> <p>-QoC and resident outcomes</p> <p>-Autonomy/loss of /impact on resident</p> <p>-Staffing – from family perspective</p> <p>-Programming – what available to improve residents’ QoL (maintain old skill, learn new)?</p> <p>-Residents helping each other</p> <p>-Unions</p> <p>-Can we provide more comprehensive LTC to avoid ER transfer?</p> <p>-Training on new model for residents and staff (what to expect)</p> <p>-Ongoing assessment</p>	<p>-Community, pod, room</p> <p>-What does it mean for families and residents?</p> <p>Positives/Negatives?</p> <p>-Community’s response to isolated residents</p> <p>-Geographical isolation vs. feelings of isolation</p> <p>-Choice – social inclusion “I can pick my own friends”</p> <p>-Programming so friends can be together</p> <p>-Segregation vs. integration (cognitive impairment, age)</p> <p>-Social environment (type and number of residents)</p> <p>Private rooms (may encourage isolation for people with dementia)</p> <p>-Issues with first available beds (families)</p> <p>-Community involvement (including intergenerational aspects, bring residents to community)</p>	<p>-Impact of clusters vs. hallways on resident/family interaction (age, cognition, gender)</p> <p>-How integration in clusters affects residents (QoL, mobility, function, social isolation)</p> <p>-Gardens</p> <p>-Social connections made and retained in clusters/pods on family and others</p> <p>-Social capital – bonding within cluster vs. bridging between</p> <p>-Physical design and relation to intimacy</p> <p>-Connections in cluster, facility, with community, community of origin, continuity, family</p> <p>-Levels of design:</p> <ul style="list-style-type: none"> • Fixed • Semi-fixed (flooring) • Non-fixed (furniture) <p>-Eden – plants, animals, children</p> <p>-Difference between integration to new and older site where increased activities/optimal ie. cleanliness, fitness, etc</p> <p>-Interior decoration – choices?</p> <p>-Family use of space – private rooms vs. common space</p> <p>-Encourage/discourage family</p>	<p>-How do different levels of cognitive function affect successful transition?</p> <p>-Who transitions effectively?</p> <p>-Families’ involvement in transition</p> <p>-How to support shared activity?</p> <p>-How do we transition from medical to social model of care?</p> <p>-How is community created?</p> <p>-How do we create community as people enter facility?</p> <p>-How do cultural norms change with admission?</p> <p>→ as admissions evolve over time from old to new facility (impacts, implications)</p> <p>-Each pod could develop own philosophy/sense of community</p> <p>-Assessment – what information is needed? Opportunity to do asset mapping? As people enter new environments? What tools are available?</p> <p>-Family asset mapping (When?)</p> <p>-How to support caregivers, residents, family, community?</p> <p>-Educate families and residents about new model – what to expect</p> <p>-Time frames and goals</p> <p>-Translation of model into concrete</p>	<p>-Levels of policy: fed→prov→facility→res/fam</p> <p>-Smoking (staff, resident, fam)</p> <p>-Interface between agriculture, fire marshal, infection control, and QoL</p> <p>-Inter-facility changes (related to policy development)</p> <p>-Union – change in positions</p> <p>-Impact on staff, ratios, qualifications</p> <p>-Barriers to engagement (laundry, cooking)</p> <p>-Lack of control of the facility:</p> <ul style="list-style-type: none"> • Facility (no fitness centre) • Regional (design constraint/large footprint requires suburb) • Provincial <p>-Ability to take residents out of facility (bus) and transportation</p> <p>-Access to medical specialized services</p> <p>-Evaluation research not required (policy change required)</p> <p>-Knowledge translation to</p>

<ul style="list-style-type: none"> -Physical and psychological risk assessment -Ongoing family involvement in care planning -How to involve residents and families in decision making -Schedules of care (wake, meals, bathe) on own time 	<ul style="list-style-type: none"> -Daycare in facility -Interpersonal involvement/strategies -What happens when resident dies? Memorial? Want to honour friendships and affect of death 	<ul style="list-style-type: none"> involvement in ADLs? -Movement between pods (socialization) -Physical design → universal design – affect on residents with different levels of impairment, is it comforting or threatening? -Private rooms and couples -Physical design differences between the different LTC facilities within and across province(s) 	<ul style="list-style-type: none"> terms over time -How will this model change over time? Baby boomers? -RCT of admission to old vs. new NW and how they transition -Compare neighbourhoods, how they function differently and why? -Effect of permanent physician assignment? Loss of family physician -Nurse practitioner holistic approach? (Utilized? Wanted?) 	<ul style="list-style-type: none"> policy makers -Tension between government policies and new approaches to care -Lack of policy regarding how to transition -Policy on education (staff, residents, family) on new model -Oral health – impact of recent policy changes to allow dental hygienists into LTCF
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