Policy Forum on Quality of Life for Residents Living with Dementia
Alberta should lead the way

Translating Research in Elder Care (TREC) in partnership with Alberta Health Services and the Alberta Ministry of Health, Continuing Care, held a policy forum on Quality of Life (QoL) for persons living with dementia in Alberta's health-funded congregate care settings. The event took place on October 9th, 2019 at the University of Alberta with a variety of stakeholder groups in attendance. The purpose of the forum was to develop a framework for improving QoL for persons with moderate to severe dementia living in long-term care (LTC) homes and designated supportive living (DSL) settings in the province.

What is a ‘Wicked Problem’?
A ‘wicked problem’ describes a complex issue that is difficult or seemingly impossible to solve or has no simple or single solution because the elements that contribute to it are interdependent, difficult to grasp, in flux or conflicting. Solving one aspect of the problem may contribute to unintended consequences or create other problems.

Around 40 attendees were on hand, including citizens living with dementia and their caregivers; long-term care home operators; government representatives from the Ministries of Health and Seniors and Housing; Alberta Health Services representatives; non-profit organizations and academic researchers.

If We Don’t Measure It, We Can’t Change It
Attendees worked together in small groups to discuss finding effective ways to define, routinely measure and improve QoL in persons with dementia living in care settings across the province. This report documents some of the rich conversations and learnings from all attendees and international guest speakers on this important day.

If there was one message from the wide-ranging discussion of the day it was that Alberta should step up and be a champion for QoL in dementia care. Alberta is well positioned to lead the way as an early adopter of routine measurement of QoL in continuing care settings as the first step toward a provincial framework including an action plan. The complexities of achieving routine measurement should not stand in the way.

As Dr. Carole Estabrooks, Scientific Director of TREC stated: “Quality of care is monitored and publicly reported routinely in long-term care homes. However, we do not routinely measure and report how residents experience their individual situation and QoL. It’s time we did.”

What is Quality of Life for Persons With Dementia?
Finding effective ways to measure and improve the QoL for persons with moderate to severe dementia is an international challenge and could be categorized as a “wicked problem.” So where to begin?
“People living with dementia can and do live high quality lives at all stages of dementia.”

Dr. Sube Banerjee, Professor and Executive Dean of the Faculty of Health at the University of Plymouth in the United Kingdom

Myth busting may be the first order of business, according to guest speaker, Sube Banerjee, Professor and Executive Dean of the Faculty of Health at the University of Plymouth in the United Kingdom who declared, “People living with dementia can and do live high quality lives at all stages of dementia.” Too many people believe that QoL automatically declines as dementia progresses, he told the Forum, and that’s not what the evidence says. “It’s possible to have high QoL with mild, moderate and increasingly severe dementia, but it’s also possible to have a terrible QoL.”

Enhancing QoL is critical work, as Banerjee stated, because it is “a more powerful predictor of mortality than all other measures.”

**DEFINITIONS OF QoL**

QoL is a broad term that encompasses a subjective assessment of both positive and negative aspects of an individual’s life, and includes the interplay between their values, spiritual and cultural beliefs with their environment, including housing, occupation, neighbourhood and other domains, with their physical and mental health. The term is understood intuitively, and is part of common discourse, but nevertheless, difficult to define and assess comprehensively.

**WORLD HEALTH ORGANIZATION DEFINITION**

“Quality of Life as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.”

**WHY MEASURING QUALITY OF LIFE IN PERSONS WITH DEMENTIA MATTERS**

**QUALITY OF CARE AND QUALITY OF LIFE?**

QoL is the ultimate goal of care for older adults with dementia in congregate settings, yet we only measure quality of care. Quality of care measures are important for maintaining quality care standards. However, they do not in and of themselves constitute QoL. Quality of care measures one aspect of a resident’s life and while it may be necessary to achieve QoL, on its own, it is insufficient.

**WHAT IS QUALITY OF CARE AND HOW IS IT MEASURED?**

Quality of Care measures the impact of health care services on health outcomes. According to the World Health Organization, to achieve this, health care services must be “safe, effective, timely, efficient, equitable and people-centred.”

In long-term care, practice sensitive quality indicators are reported routinely, such as antipsychotic use without psychosis, worsening pain, decline in mood, so they can be used to assess the impact on resident health outcomes across different units and facilities.
Clinical assessments measuring a resident’s disease trajectory are not necessarily relevant to QoL: “Dementia symptoms can’t be used as proxies to detect QoL,” Banerjee cautioned. “It’s time to move away from cognition, behaviour and function questions” since “the link between symptoms and QoL is not clear, simple or predictable.”

Guest speaker, Dr. Kate de Medeiros, O’Toole Family Professor of Gerontology at Miami University in Ohio noted that too often the testing of QoL interventions miss the mark. Randomized-control trials for long-term care programming may not be as well suited as more qualitative research methods for capturing QoL data. Randomized controlled trials are well set up to study pharmaceutical interventions, for example, but not designed for assessing social and environmental interventions, so it’s no surprise that they don’t do a good job of it: “What is a dose of poetry or theatre?” she asked.

QOL IS WHAT MATTERS MOST TO DEMENTIA-RESIDENTS AND THEIR CAREGIVERS

QoL is what matters most to people with dementia and their families, friends and caregivers – thus, it is what should drive interventions and should matter to clinicians, policy makers and researchers.

QoL measures allow for a scientific assessment for evaluating the effectiveness of specific interventions. We can also learn what constitutes a good QoL and how to maintain and enhance it from persons with dementia and their family and friends.

IMPROVE CARE EFFICIENCY

Measuring QoL for people living with dementia may help identify specific areas for intervention, and ultimately improve levels of comfort, contentment, happiness and joy in their lives, and the lives of their family, friends and caregivers. Measuring QoL, however, is also important to evaluate care and service outcomes and cost-effectiveness.

Budgets, staff time and program availability are limited, so it is critical to have a valid QoL measure available to understand which QoL interventions are effective, and in what manner, to maximize resources and attain improved QoL for residents.

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QoL Measurement in Dementia
HOW CAN WE MEASURE QUALITY OF LIFE IN PERSONS WITH DEMENTIA?

- DEMENTIA QUALITY OF LIFE (DEMQOL)

There have been numerous measures developed to assess QoL for people living with dementia with robust methodology and improvements in instrumentation over time. It is an evolving field.

One of the health-related QoL measures created for persons living with dementia is the DEMQOL, which is administered directly to the person living with dementia. There is also a version that can be administered to the person’s caregiver, the DEMQOL-Proxy, when dementia is more severe.

While there is no consensus on the best QoL measure to employ, the DEMQOL was created specifically for use across the range of dementia severity, for various types of dementia and for use in different care settings. Importantly, DEMQOL keeps the views of dementia residents at the forefront and employs a multi-disciplinary and phased approach with a high quality methodology.

According to Banerjee, DEMQOL studies have demonstrated that it has high acceptability, high feasibility, high internal consistency, good test and retest reliability, and good evidence of validity. It also enables clinical and economic evaluation: “It’s a unique system ready to use in dementia,” he stated.

The DEMQOL-CH (Care Home) version was of particular interest to the forum attendees since it was developed for use in care homes and can be completed by front-line staff – thus enabling routine collection. It is the most recently developed tool of the DEMQOL system and has been validated in a number of care homes in the United Kingdom.

- FACTORS AFFECTING IMPLEMENTING A QOL MEASURE IN ALBERTA

Forum attendees were asked to list factors that would affect the implementation of a QoL measurement tool in Alberta and that would need to be explored further:

- Staff related factors: training to use the tool; front-line staff buy-in; care aides may feel more valued and engaged, may feel their role elevated
- Barriers: time away from front-line care; care aide ESL
- Administering the tool: Frequency to have a robust QoL; inclusion of a caregiver QoL measure
- Data: storing the data and data analyses need to be sorted; feeding back the data

- TREC RESEARCH UNDERWAY

TREC has begun the groundwork to test the DEMQOL-CH measure in Alberta long-term care facilities to determine if it is suitable for residents and whether it is feasible to routinely collect. This is an early step toward routine measurement of QoL in persons with dementia.

Importantly, DEMQOL keeps the views of dementia residents at the forefront and employs a multi-disciplinary and phased approach with a high quality methodology.
TREC will study the feasibility of having care aides administer the DEMQOL-CH. They will then assess the kinds and quality of the data collected using this measure, costs, barriers and facilitators. The team will also build strategies for how best to implement the DEMQOL-CH across nursing homes (NH) in the province and beyond – spreading and scaling the initiative – in collaboration with facility decision-makers, care staff, people with dementia and their families and caregivers.

**WHAT FACTORS CONTRIBUTE TO QOL?**
Forum attendees created a list of factors that contribute to QoL that included:
- Autonomy, flexibility and choice
- Social connection and engagement
- Purpose and joy, quality of the moment
- Personal histories and values
- Homelike environment
- Managed risks

**Objectives of the proposed study (submitted to CIHR in September 2019):**
1. Determine feasibility of having care aides administer a dementia-specific QoL instrument in NHs
2. Assess psychometric properties of the DEMQOL-CH and quality of data collected by care aides
3. Build strategies to implement the DEMQOL-CH in NHs, in collaboration with decision makers, NH managers, care staff, people with dementia and family/friend caregivers

**Benefits of the proposed study**
- Validate a dementia-specific measure with Canadian NH residents with dementia
- Overcome barriers to assessing QoL with NH residents
- Monitor NH performance longitudinally
- Identify and close performance gaps
- Improve quality of life for the frail and extremely vulnerable older adults
- Monitor impact of diverse strategies and policy initiatives for QoL

**Why use the DEMQOL-CH?**
- Most rigorously developed and validated QoL tool for use with people with dementia
- Designed to work across all dementia subtypes, stages of dementia and care settings
- Instructions and items modified for care aides
- Only instrument adapted for routine administration
WHAT ARE THE STRATEGIES AND INTERVENTIONS FOR IMPLEMENTING QOL PROGRAMS?

Moving beyond QoL measures, how do we implement programs that improve QoL for residents with dementia in long-term care facilities? “Quality of life in long-term dementia care is about creating environments that are rewarding, stimulating and allow people to express themselves,” said Dr. Banerjee.

COMMON ELEMENTS IN SUCCESSFUL QOL INTERVENTIONS

According to de Medeiros, the following are a few of the critical factors in successful QoL interventions:

- Including volunteers
- Residents contribute to intervention development
- Allowing for opportunities for residents to reminisce
- Engaging smaller groups (of residents, staff, volunteers)

WHAT ARE THE CRITERIA FOR QOL INTERVENTIONS AND STRATEGIES?

Attendees were asked what they thought constituted important factors for implementing QoL interventions and strategies and came up with the following:

- Identify residents’ interests from careers, families and the individual
  - Look into the past and present for preferences
- Focus on individual goals
- Prioritize meaning, meaningfulness, connections and social interaction
  - Between residents, staff, and family and friends
- Prioritize purpose, autonomy, antidotes to boredom and loneliness
- Residents should own and be engaged in planning and implementing QoL programming and make a meaningful contribution
- Training for staff (person-centered care, communication); Staff buy-in (direct care, management); Engage the external community
- Linked to other outcome measurements and evaluation
- Incentivized at the funding level

“Quality of life in long-term dementia care is about creating environments that are rewarding, stimulating and allow people to express themselves.” ~ Dr. Sube Banerjee

Policy Forum on Quality of Life for Residents Living with Dementia
Alberta is well positioned to recommend and test a province-wide approach for addressing QoL in persons with dementia. How do we get there?

Two Working Groups were created to work on 1) testing the feasibility and implementation of a QoL measurement; and 2) preparing a guide of potential strategies and interventions.

1. TESTING AND IMPLEMENTATION OF MEASUREMENT

Select Forum attendees have agreed to work toward creating a long-term plan to implement QoL measurement in long-term care (and possibly DSL) facilities across Alberta, helping Alberta to be an early adopter and leader in QoL measurement and improvement for persons living with dementia in long-term care facilities.

2. GUIDE OF POTENTIAL STRATEGIES, INTERVENTIONS

A next step is to commission a review of evidence-informed strategies for QoL programming. Evidence-development is part of the strategy. The goal would be to develop a suite of evidence-informed strategies that could be implemented and evaluated.

This suite of QoL interventions would be organized by core elements that the interventions address (such as enhancing social connection, meaningfulness, autonomy or belonging) and the problems the interventions are meant to address (e.g., boredom, loneliness), along with a description of the possible programs that have been undertaken and any evidence of their impact on QoL.

Such a suite would also enable facilities to learn about new QoL interventions from around the world. The goal would be to broaden the scope and suite of opportunities and showcase the best practices of QoL interventions. It would also tackle sustainability issues and organizing costs.

LEVERAGING EXISTING INNOVATIONS

The working group could also look at leveraging existing innovations and projects already underway in the province to learn best practices and help facilitate the spread and scale of QoL interventions already proven or underway. These opportunities could be leveraged through innovation and practice grants to advance QoL implementation across the province. The DEMQOL-CH could be used to test some of these projects to expand our knowledge base further related to the evidence base.
TRANSLATING RESEARCH IN ELDER CARE (TREC), one of the drivers of the QoL work in Alberta, is an applied health services research program that partners researchers, knowledge users, policy makers and those most affected – older adults living in long-term care homes and their families across Canada. TREC aims to improve elder care by producing knowledge and by moving knowledge to action.

WHAT WE DO

TREC’s mission is to improve the lives of vulnerable persons living in long-term care homes by creating solutions in the areas of:

- Improving quality of care and quality of end-of-life care
- Enriching the daily lives of people living there
- Improving quality of work-life for staff
- Assisting managers, administrators, owners and policymakers with evidence-informed decision-making; for example, by producing gold standard evidence using clinical trials

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Changing the Story

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# APPENDIX

## Policy Forum Attendees

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<thead>
<tr>
<th>Name</th>
<th>Role</th>
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<tbody>
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<td>Carol Anderson</td>
<td>Executive Director, Continuing Care, Edmonton Zone, Alberta Health Services</td>
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<tr>
<td>Eddythe Andison</td>
<td>Vice-President Clinical Support, Good Samaritan Society</td>
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<tr>
<td>Sube Banerjee</td>
<td>Professor and Dean, University of Plymouth</td>
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<tr>
<td>Charlotte Berendonk</td>
<td>TREC Managing Director</td>
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<tr>
<td>Laurianne Blais</td>
<td>Companion – Lionel Blais</td>
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<td>Lionel Blais</td>
<td>Person living with dementia – Citizen</td>
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<tr>
<td>Judy Brown</td>
<td>Family representative on Quality Council – Citizen</td>
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<tr>
<td>John Cabral</td>
<td>Assistant Deputy Minister, Health Services Delivery Division, Alberta Health</td>
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<td>Stephanie Chamberlain</td>
<td>Postdoctoral Fellow, Department of Family Medicine, University of Alberta</td>
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<td>Krista Connell</td>
<td>TREC Consultant</td>
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<td>Kyle Corbett</td>
<td>TREC Administrative Assistant</td>
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<td>Kate de Medeiros</td>
<td>Associate Professor, Miami University</td>
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<td>Brittany Elliot</td>
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<td>Carole Estabrooks</td>
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<td>Faye Forbes</td>
<td>Person living with dementia – TREC VOICES – Citizen</td>
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<tr>
<td>Kathy Fortunat</td>
<td>CEO, Sherwood Care</td>
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<td>James Gaehring</td>
<td>Person living with dementia – Citizen</td>
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<td>Ellen Susan Henwood</td>
<td>Companion – Faye Forbes</td>
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<td>Matthias Hoben</td>
<td>Assistant Professor, Faculty of Nursing, University of Alberta</td>
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<td>Laura Hughes</td>
<td>Postdoctoral Fellow, University of Sussex</td>
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<td>Jeanine Kimura</td>
<td>Director, Quality and Performance, Carewest</td>
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<td>Leah Lechelt</td>
<td>Executive Director, Christian Health Association of Alberta</td>
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<td>Don McLeod</td>
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<td>Kathleen O’Grady</td>
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<td>Renate Sainsbury</td>
<td>General Manager, Lifestyle Options Retirement Communities</td>
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<td>Audrey Sand</td>
<td>Director, Innovation and Change Management, Capital Care</td>
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<td>Hazel Smelt</td>
<td>Director of Care, Extendicare Mayerthorpe</td>
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<td>Cheryl Smith</td>
<td>Family Caregiver – Citizen</td>
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<tr>
<td>Trina Thorne</td>
<td>Graduate Student, Faculty of Nursing, University of Alberta</td>
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