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.

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 discussed effective ways to define, routinely measure and improve QoL in persons with dementia living in care settings across the province.

If there was one message from the wide-ranging discussion it was that Alberta should step up and be a champion for QoL in dementia care.

What is quality of life for persons with dementia?

Finding effective ways to measure and improve QoL for persons with moderate to severe dementia is an international challenge.

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 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.”

“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
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.

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.

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.

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. 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.

The DEMQOL-CH (Care Home) version was developed for use in care homes and can be completed by front-line staff – thus enabling routine collection.

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.
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.

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 in the province and beyond.

WHAT ARE THE STRATEGIES AND INTERVENTIONS FOR IMPLEMENTING QOL?

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 guest speaker Dr. Kate de Medeiros, O’Toole Family Professor of Gerontology at Miami University in Ohio, the following are a few of the critical factors in successful QoL interventions:

- Include volunteers
- Residents contribute to intervention development
- Allow for opportunities for residents to reminisce
- Engage smaller groups (of residents, staff, volunteers)

COMMON CHALLENGES

According to de Medeiros, common challenges for implementing QoL interventions include:

- Staff time
- Over-emphasis on safety instead of autonomy
- Over-emphasis on physical tasks instead of social interventions

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 resident’s interests from carers, 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
- 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
NEXT STEPS

Alberta is well positioned to recommend and test a province-wide approach for addressing QoL in persons with dementia. How do we get there?

In moving forward on concrete actions to test the feasibility of a measurement tool and identify some solutions to the challenges identified, and the opportunities we can leverage, we hope to move forward a proposal for a province-wide approach, and determine if that is the best way to prioritize QoL for this group. Two Working Groups will work on 1) testing the feasibility and implementation of a QoL measurement; and 2) preparing a guide of potential strategies and interventions.

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