Illuminating Resident Wellness through OLTCA

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On February 13, 2013, the Ontario Long-Term Care Association (OLTCA) held its fourth annual Applied Research and Education Day — titled “Building on Evidence: Catalysts for LTC Transformation” — at the Fairmont Royal York Convention Centre in Toronto. This year’s event promoted quality, safety, policy, and leadership as broad themes intended to inform the 400 long-term care (LTC) home residents, researchers, students, policymakers, front-line care partners, and aging care product innovators in attendance. I felt privileged to attend the forum and present my Master’s work on resident wellness as perceived by residents living in LTC homes.

The OLTCA focuses on connecting people within LTC homes with information, other people, and community resources. To build and strengthen Ontario’s LTC communities, the OLTCA holds events that promote research, and creates opportunities for research, knowledge translation and transfer, student development, and professional networking.

At 7:30 on an icy Friday morning, the excitement was tangible. The warm welcome from conference staff and an accelerating enthusiasm from delegates was more than I could ask for (aside from a steaming cup of java) to get the day started on the right foot.

As the crowd grew, attendees made their way into the main hall for the opening plenary, past the spot where I had set up my station alongside other poster presenters.

Throughout the day, discussion and evaluation of poster sessions took place between concurrent sessions featuring topics on culture change, quality indicators, and safety.

I was grateful for the opportunity to dialogue with residents representing OARC (Ontario Association for Residents’ Councils), front-line staff (i.e., administrators, PSWs, social workers, nurses, recreation therapists, dietary workers, and others), researchers interested in aging and health systems, as well as formal and informal care partners.

Attendees who inquired about the Resident Wellness Model that emerged from working with partners at Specialty Care LTC homes acknowledged that the model reflected their own experiences. I was happy to share with them highlights of our poster, which included a flower that served as a beautiful metaphor for the ways resident wellness is nurtured by its environment and relationships. The poster also listed six recommendations for supporting resident wellness in LTC homes (see page 2).

At the end of the day, the 52 poster presentations were adjudicated based on quality of research, significance to LTC or theme of the research day, timeliness and usefulness of findings, and clarity of content and visual appeal. Our poster, titled “Wellness from Perspectives of Residents Living in Long-Term Care Homes: A Participatory Action Research Approach,” was selected to receive the Residents’ Choice poster award, presented by Josie Ince, an LTC home resident and President of OARC. Also, of the 26 student posters, ours was voted “Best Student Poster” by conference delegates.

These awards would not be possible without the support of residents, staff, and care partners at Specialty Care LTC homes, faculty and staff at MAREP, partners from Ontario College of Art and Design, donors, University of Waterloo, and delegates who nominated our poster for recognition. Thanks to all for recognizing and promoting a vision of resident wellness in LTC homes!

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A Model of Resident Wellness

Through critical reflection and broader community input, our participatory action research team, made up of residents, family members and staff, identified four themes supporting resident wellness:

- my relationships
- my home
- my self
- my activities

My Relationships: “Well” Relationships
Strong relationships with family, staff (and volunteers), residents, faith, and one’s community contribute to enhancing the perception of resident wellness.

My Home: A “Well” Home
Residents spoke about the home itself and aspects of the home that made them feel well. Some of their wellness experiences were about things they felt and others were features of the physical space. These sub-themes were named spirit of the home and body of the home, respectively. The spirit of the home was meant to encompass an overall feeling or a lived sensation of being while in the home. Four main parts identified with a home’s “spirit”: smells and sounds; having a say and choice; safety and security; and morale. The body of the home encompassed physical aspects of the home’s space, like the qualities of the physical space, personal space, clean space, and beautiful space.

My Self: A “Well” Being
The many ways we perceive ourselves, how we relate our experiences with one another, what we value about ourselves, and our opinions of the world around us are important for fostering wellness. Residents expressed that reflecting and sharing a sense of self, having positive evaluations of self, having a positive outlook, and making time for self were valuable for experiencing resident wellness.

My Activities: Living “Well”
According to residents, rest, meal times, personal care, and leisure and celebration supported them in feeling well. Leisure meant a meaningful occupation of time (with others or by oneself) and, like the other themes, was a meaningful conduit for enriching a well home environment, well relationships, and a well self.

Implications of the Resident Wellness Model
OLTCA’s applied research and education day demonstrated that many practices exist for health and well-being promotion. Interestingly, an article that examines the integration of wellness approaches in allied health policy and practice reports that current wellness approaches are misaligned with the medical approaches adopted by most institutions today (Breen et al., 2008). Our challenge as members of LTC communities is making time more meaningful and supporting experiences of wellness as residents define it. This means we all have a role in nurturing all relationships in order to enhance resident wellness and support living in LTC homes.

It was interesting to find that leisure permeated each of the themes outlined in the Resident Wellness Model and every part of resident life. Experiences of wellness from residents’ perspectives, inclusive of leisure experiences, enabled us to highlight resident definitions in the co-creation of a deep understanding of resident wellness in efforts to support well LTC homes.

Recommendations for Supporting Resident Wellness
To glean more feedback from the broader LTC community, we hosted a community forum to develop recommendations:

1. Consider the needs and “voices” of all residents, including those who require more support or who are less verbal, and meet those needs in creative ways.
2. Consider ways to meet personal space preferences.
3. Find ways to create more pleasurable dining.
4. Familiarity is important — reconsider decisions to move residents when their health status changes.
5. Ensure adequate staffing.
6. Ensure access to the outdoors.


Kimberly Lopez with our “Resident Wellness” poster, which won the Residents’ Choice Award and Best Student Poster Award on February 13, 2013, at OLTCA’s annual Applied Research and Education Day (see page 1).
Living Well with Dementia: Challenging the Myths and the Stigma

On January 21, 2013, MAREP held an awareness event comprising a public lecture and an exhibition of community resources. The event received an overwhelming response from the University of Waterloo community, our MAREP partners, as well as the general public. The lecture component featured Dr. Peter Whitehouse, Professor of Neurology at Case Western Reserve University and a MD-PhD in Psychology; Ann Marie Wilson, a family partner in care and spokesperson; and Mary Beth Wighton, a person living with frontotemporal dementia and a dementia advocate. See also Mary Beth’s personal story on page 4.

Working closely with many individuals with dementia, Dr. Whitehouse recognized that clinical labels often limit people with dementia to realize their full potential and discourage care partners who are supporting relatives in living purposefully with their diagnosis. This diagnosis — dementia, Alzheimer’s disease, or another related dementia — is a powerful term that shapes one’s perception and attitudes about the disease, oneself, and one’s experiences. For instance, the music a person with dementia listens to becomes “music therapy” after the diagnosis, and not just “music.” Alzheimer’s disease and dementia are not simply biological brain pathologies but are also connected to the broader social context.

Dr. Whitehouse challenged the diagnosis of Alzheimer’s disease, as it overlaps considerably with experiences of aging. The picture becomes more ambiguous as a continuum of Alzheimer’s disease emerges, where clinical symptoms may not reflect the pathological changes in the brain. Dr. Whitehouse commented, “We may all be developing Alzheimer’s disease — just asymptomatic Alzheimer’s disease.” Given the complexities associated with illnesses that cause dementia, he proposed that “perhaps nobody deserves a clinical label.”

Speaking from her personal experience as a family partner in care, Ann Marie Wilson also challenged the stigma of dementia. Carl, Ann Marie’s husband with dementia, is fortunate to have her as his biggest supporter. Ann Marie claimed, “Carl is anything but frail and elderly.” Contrary to what many people may assume, persons with dementia are able to acquire new skills, given the right resources. Carl is a living example: he learned to play the xylophone in the Sunnyside Day Program in Kitchener. In addition, persons with dementia are also able to stay socially, mentally, and physically active with the proper support. Carl regularly exercises and contributes to creating educational materials in dementia care. In particular, he took part in creating MAREP’s By Us For Us guides.

Ann Marie strongly encouraged persons with dementia and their care partners to connect with support groups and get involved. As two of MAREP’s longstanding partners, Ann Marie and Carl have been involved in many initiatives, such as the A Changing Melody forum, the Journey of Dementia through Photography project and, as noted above, numerous By Us For Us guides. They are also active in their local Alzheimer Society chapter and have been featured in the local media.

As a person diagnosed with frontotemporal dementia at 45, Mary Beth Wighton encountered one obstacle after another in adjusting to “a new norm,” such as making transportation arrangements after having to give up her licence. Since receiving her diagnosis, Mary Beth’s emotions have ranged from disbelief to anger to sadness to grief. “Carpe diem” (or “seize the day” in English), has become Mary Beth’s motto in her quest to live well with dementia. With the support of family and friends, Mary Beth is determined to live life to its fullest and with dignity. She encouraged persons living with dementia to first define what living well means for them, and then work with professionals to create a holistic plan that makes their dreams come true. She noted that every journey will be different, so it is important to work in partnership with persons with dementia, respect their perspectives and desires, nurture continued abilities, and develop new skills. One of the more tangible ways for Mary Beth to live purposefully is by getting involved with MAREP. She actively contributes to MAREP’s blog and currently serves on the advisory team of a self-management project in collaboration with researchers at Lakehead University.

Like Dr. Whitehouse and Ann Marie, Mary Beth uses her personal experience to challenge the predominant stigma. She strongly supports public events like this one, so that myths and misunderstandings can be addressed and persons with dementia can continue feeling included and valued.

Please continue to partner with us to dispel myths of dementia and support individuals with dementia to live meaningfully!

Save the Date: May 31

“Re-Imagining Dementia through the Arts”
MAREP will be hosting a community lecture and art exhibition on Friday, May 31, from 7 to 10 pm at a location to be announced. Speakers will include:

- Judith Leitner, a family partner in care and photographer who captured experiences of living with dementia
- Dr. Lisa Meschino, MAREP post-doctoral fellow, who has been examining the impacts of a community art program – Gather at the Gallery – for persons with dementia, family members, and artists
- Dr. Sherry Dupuis, Director of MAREP, who has been working with a team of researchers, persons with dementia, family members, artists, and actors in creating an alternative discourse of dementia

Art exhibited throughout the month of June will include photographs by Judith Leitner and Diego Quattrociocchi, pottery and glass work from participants of the Alzheimer Society of KW’s Gather at the Gallery program, an art installation created by Dr. Lisa Meschino, and placards created by persons with dementia and family members in collaboration with local artists.
Playing on the Dementia Team
by Mary Beth Wighton

Growing up I was an excellent athlete, playing basketball, volleyball, and soccer. Therefore, when I was diagnosed with frontotemporal lobe dementia, it really didn’t surprise me that I wanted to be part of a team fighting for people with dementia. Just after diagnosis in September 2012, I was made aware of MAREP. I made contact and a meeting time was set up to discuss a possible partnership.

One of the opportunities suggested by Lisa and Jessica at MAREP was to speak at the Living Well with Dementia public lecture on January 21, 2013 (January is Alzheimer Awareness Month). I jumped at the chance! For many years, I’d been part of a training team for a large, well-known software company and although I hadn’t been in front of a classroom for quite a while, this sounded like fun.

The big day arrived. My family chattered nervously as we walked into the university building. The buzz had already started. I love that energy – the feeling of nervousness, excitement, yet calmness. It brought me back to my days of playing an extremely important game of basketball. I couldn’t wait to play!

As I adjusted to the noise and the crowd of people, I realized that I was sitting beside Brenda Hounam, a recent recipient of the Queen Elizabeth II Diamond Jubilee Medal. I could hardly believe it! A MAREP partner since 2001, Brenda has helped create the “By Us For Us” series and many other important tools for those with dementia. I must admit that I was a bit in awe. Brenda gave me a warm welcome and told me she was looking forward to my speech.

I’m sure my eyes widened on seeing Carl and Anne Marie Wilson, well-respected spokespersons and advocates for people living with dementia. This dynamic duo has helped create tools with MAREP. I knew that Anne Marie would be speaking about having a meaningful life as a family partner in care of Carl, who has dementia. Just down from them sat Dr. Peter Whitehouse, who would be discussing living well with dementia and challenging the myths. He, too, is well-known and admired for his work.

Before I knew it, I was looking at the audience, feeling the warmth and encouragement as I began to speak. Family and friends dispersed throughout the crowd were cheering me on. My girls were in the front row, proud as peacocks. I knew that it didn’t matter how the speech went, this crowd would never let me fail. As I finished, I received a standing ovation. A standing ovation! I felt like the person who just sunk the winning shot in the last seconds of the game.

People came up to congratulate me and give me a hug. We had won.

On reflection, I realize that my analogy of being part of The Dementia Team works well for me. The captain is Brenda, encouraging all members and providing wisdom when things get tough. Anne Marie plays the supporter; Dr. Whitehouse serves as the member of the medical community; MAREP functions as the team manager. Family and friends can play many positions. Carl and I are the scorers. Our job is to take the basketball and shoot it into the hoop.

I didn’t try out for The Dementia Team; I was given membership. But, like always, I will try to work hard and support my teammates. What is the opposition team, you ask? Dementia. I have a great team and am thankful for my fellow players. Go team go! Go team go!