

Mapping the Dementia Journey

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The purpose of this study was to “map the dementia journey” in plain language from the perspectives and experiences of people living with dementia, care-partners, and health service providers in Ontario. The project aims to capture the experiential elements of the journey, and align these with key points in the care pathway.

Research Methodology

Using a qualitative approach, the researchers worked with people living with dementia and care partners to create living “maps” of their dementia journey. Twelve focus groups were held across Ontario, comprised of 14 people living with dementia, 24 care partners, and 14 health and social care providers. Using a mapping concept, participants were provided an open canvas with road, and determined various key milestones and experiences along the “journey” of the road using pinpoints. Using road signs, participants then chose the sign that represented that aspect of the journey, and had them describe what the road looked like for them at that point. A workshop was held bringing together stakeholders to review preliminary maps and provide additional comments. All the data was then analyzed, and presented as a subway map.

Research Findings

There were many factors to consider in the data analysis, including the diversity of the dementia journey for each person, the interconnectedness of aspects of the journey, the complexity of the journey, and the dimensionality of the journey. Finally, the subway and road analogy was decided upon. This analogy, we felt, captured the diversity, complexity, interconnectivity, and dimensionality of the dementia journey.

There were four aspects or themes of the journey that we chose to focus the interconnected dementia journey on: The System Journey, Changing and Adapting, Caring for Myself, and Relationships in the Community. The overview of this journey can be found in Figure 1.

1.0 The System Journey

The first theme, The System Journey, represents interactions within the health and social care system; particularly the medical and long-term care systems. The system journey helped to identify 11 subthemes that capture places where people living with dementia and care partners interact with the formal care system, government legislation, and other support services needed throughout the dementia journey.

Figure 1: Dementia Journey Subway Map



Beginning the steps of the dementia journey, *Testing and Assessment* is described as ‘roundabout’, as assessments did not always lead to clear diagnosis of dementia. A *Diagnosis* of dementia can be described as ‘steep down road’, as many participants initially believed a diagnosis of dementia implies immediate decline in cognition, knowing the disease is progressive, although this was not often the experience for many people. Once a diagnosis was given, participants wanted more information, which was described as *Finding out More*. This was described with the street sign “entering the school zone” to represent not being alone on their journey. Participants in this study went through a period of responding to the diagnosis, and trying to come to terms with what a diagnosis means. Many participants received very little information from their health care providers. The need for information, education, and awareness was stressed as being important throughout the journey, for all people involved.

Planning Ahead was also reported. Planning ahead described moving in one direction, as there is no opportunity to go back. The participants used the road sign “share the road” to describe how they *Connected With Services* within the community. These community services also connected participants to other individuals going through the same experiences. These services related to 1) education and information; 2) support groups; 3) help around the home’ and 4) help with care of

the person living with dementia. Participants also shared the difficulties of *Navigating the System*, especially when challenges arise of knowing what information and resources are available.

While many people living with dementia are able to stay at home, participants described *Staying at Home* with the road sign of 'falling rocks'. Remaining in the home included utilizing many support services. However, situations of crisis may still occur, and key concerns were recognizing the need for help and accepting it. Furthermore, *Alternative Living Arrangements* were sometimes necessary for the care of an individual living with dementia.

Other aspects not previously mentioned throughout The System Journey included *Giving up Driving*, *Palliative Care*, and *Leaving a Legacy*. Leaving a legacy encompassed creating memories and engaging in advocacy work to change the landscape of dementia and address stigma.

2.0 Changing and Adapting

Changing and Adapting referred to the kinds of changes that might occur along the dementia journey, and how people responded and adapted to those changes. One of the first changes recognized throughout the dementia journey was *Crystallizing Moments of Awareness*, when people knew something is not quite right, but they didn't think something was quite wrong either. It was the process when key signs or symptoms were experienced, but not recognized until they occurred with more regularity. A *Catalyst* was a key event beyond crystallizing moments of awareness that made the person or family seek help.

Participants also illustrated that throughout their dementia journey, many people experienced more than one *Response to a Diagnosis*, including 'accepting' a diagnosis, and yet also 'fighting' a diagnosis' in order to live as well as possible. The adjustment period, *Adjusting to a New Normal*, proved to be challenging as 'normal' is constantly changing. A person must then *Reconstruct the Future*, and *Live for Today*, which was the choice to enjoy the moment, regardless of the future. Lastly, *A Changing Identity and Sense of Self* was represented by the 'pedestrian crossing' sign; the participants described seeing themselves differently because of dementia. This change is not always negative, as many individuals found purpose and meaning in their lives as their sense of self shifted and evolved.

3.0 Relationships and Community

The third theme, Relationships and Community encompassed other people and the interactions with others throughout the dementia journey. This theme focused on the importance of family, friends, and community throughout the dementia journey.

The first subtheme included *Telling Others About the Diagnosis*, which was represented as a 'winding road sign, since this decision was not always straightforward. While some chose not to share their diagnosis, others were very open about their diagnosis, indicating that this was helpful so that others would know why they might be experiencing challenges. Consequently, *Changing Relationships* are evident throughout the dementia journey; Care partners described challenges in communication, and a corresponding lack of intimacy and closeness, while people living with dementia also had concerns for changing familial relationships. Despite changing relationships,

those affected by dementia also *Build Circles of Support*. Circles of support described both the intentional and unintentional ways that people were supported through the dementia journey. Lastly, *Challenging Stigma* was described by a person with dementia: “There is no other disease that excludes the person with the disease more than this one”.

4.0 Caring for Myself

The final theme, ‘Caring for Myself’ and ‘Focusing on me’ captured things that people living with dementia and care partners did to stay well and to care for themselves. Subthemes that emerged under these contexts included *Keeping a Positive Attitude*, and *Coping with Emotions, Stress, and Anxiety*. One way that participants could ensure this is by also *Engaging in Meaningful Activity*. Meaningful activity was described as beneficial in supporting people to continue their journey in a positive way. Lastly, this theme explores *Finding Purpose and Meaning*. Those living with dementia described how they found purpose and meaning in life; this was both despite and because of a diagnosis of dementia. For many living with dementia, advocacy and changing stigma highlighted purpose and meaning in life. For care partners, many found meaning in the relationships they developed. Both those living with dementia and care partners described feelings of accomplishment, such as developing patience, caring for someone, or speaking publicly and advocating.

Reflections

Mapping out the dementia journey will never entirely capture the experiences of people living with dementia and their care partners since everyone is unique and diverse. However, key elements captured were common themes along the dementia journey. Using visual methods to describe the dementia journey provided opportunities to present the complexity, interconnectivity, diversity, and multidimensionality of the dementia journey, and to enable the users to choose the aspects of the dementia journey that fit with their experiences, rather than providing a prescriptive journey.

In our attempt to capture the key elements of the dementia journey, there are inevitably aspects that we have missed. Part of this will be resolved as we hopefully continue to gather data and explore more experiences of the dementia journey. In particular, future work aspires to engage different cultural and diverse groups, and we can ensure the representation of the dementia journey captures key elements of these experiences as well.

This project, “Mapping the Dementia Journey”, has provided a wealth of rich and detailed data, stories, and information about people’s experiences along the dementia journey. Using innovative visual and arts-based methods can provide greater understanding of the dementia journey from the experiences of those travelling this journey. It is our hope that this beginning can form a firm foundation to create important resources and tools to support and assist people during their journeys through dementia.