



Learnings from an evaluation of an online learning resource for early-stage caregivers of people living with dementia: ‘IncludeMe™ A Starting Point for Dementia Caregivers’

There are limited community-based resources to support early-stage caregivers of people living with dementia (PLWD). Without support these caregivers often struggle to cope. Research says these caregivers would benefit from accessible services, information, and caregiver education including how to care for themselves.

IncludeMe™ A Starting Point for Dementia Caregivers is an online asynchronous, gamified, scenario-based learning resource that aims to improve the knowledge, skill, and attitude for early-stage caregivers of PLWD or persons showing signs of dementia in a way that is acceptable, accessible, and useful to them.

“After engaging with the IncludeMe™ A Starting Point for Dementia Caregivers learning resource, 25 caregivers felt more prepared for caregiving and more confident in their ability to respond to disruptive behaviours of PLWD. Most of these 25 caregivers found the training inclusive and useable in terms of ease of learning, however acceptability could be improved by delivering content that is new and easy to navigate”



Project Overview

Caregivers play an integral role in supporting and caring for people living with dementia (PLWD), yet many caregivers feel ill prepared and uninformed about how to navigate their caregiver role.¹ Early-stage caregivers to PLWD have unique stage-specific caregiving needs that are often unmet due to a gap in available and accessible resources targeted to this group of caregivers.² Many caregivers of PLWD find internet-based education interventions an appropriate and effective way to learn and get support, yet few of these learning resources have been designed for, or tested with early-stage caregivers for PLWD.^{3,4}

Iris the Dragon and Addiev Corporate Training co-lead the development of a new learning resource called **IncludeMe™ A Starting Point for Dementia Caregivers** – an online gamified learning resource that aimed to improve access, understanding, and implementation of high-quality dementia guidance for early-stage caregivers using accessible technology not limited by time and place.

The **IncludeMe™** learning resource was developed using three phases of the ADDIE method for instructional design, *Analysis*, *Design*, and

Development.⁵ Partner organizations and individuals bringing unique expertise and perspectives to developing the resource included both men and women, persons with Indigenous heritage, rural caregivers, a new caregiver, and professionals in dementia support and care. These collaborators participated in a two-day Training Board (*Analysis Phase*) and provided feedback on the curriculum (*Design Phase*) and blueprint of the online learning resource (*Development Phase*).

Twelve people from partner organization participated in the Training Board (*Analysis Phase*) and identified the training needed to meet a desired level of competency (e.g., awareness, knowledge intake, performance, attitudinal change).

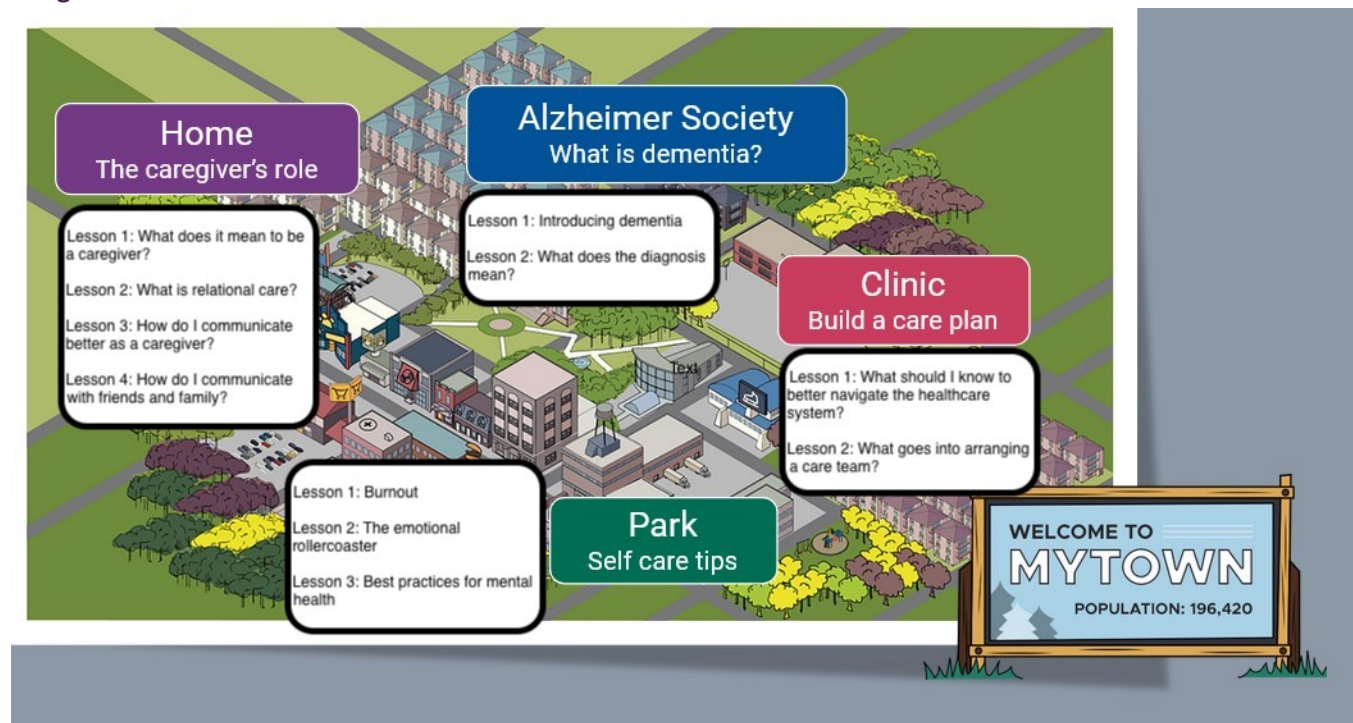
Iris the Dragon and Addiev Corporate Training, then took this feedback and drafted a curriculum, requesting partner feedback in an iterative process (*Design Phase*). The resulting curriculum focused on learning in four areas:

1. Knowledge about dementia including the correct terminology to communicate to others about the condition;
2. Navigating the healthcare system and local community supports to initiate a circle of

- relational care for the PLWD;
3. Preparing a care plan, plus a circle of relational care for the PLWD; and
 4. Develop a plan for personal self-care and social connectedness.

Iris the Dragon and Addiev Corporate Training then created scenarios that reflected the experiences of a caregiver in the four identified modules to engage the learners through the use of story (*Development Phase*). The final version of the evaluation-ready pilot learning resource consisted of four modules, with two to four lessons in each. The resource was designed to allow people to navigate the program in a “choose your own adventure” format (see Image 1).

Image 1: Outline of Pilot for IncludeMe™



What have we done?

As part of our research portfolio investigating Aging in Society, we were asked to evaluate the newly developed learning resource. We used a mixed-methods approach – including before/after training questionnaires and focus groups with participants. The objective was to understand the effectiveness and impact on people using **IncludeMe™ A Starting Point for Dementia Caregivers** and provide insights to support its refinement, scale and spread. This study was reviewed and approved by the SouthLake

Regional Health Centre Research Ethics Board (REB #: S-023-2324).

Seventy-six new caregivers completed a *before-training* questionnaire that measured attitudes, knowledge, and perception of skills through psychometrically tested scales. After thirty days of access to **IncludeMe™**, twenty-five of the seventy-six participants completed an *after-training* questionnaire which included the scaled measurements from the *before-training* questionnaire, as well as open-ended questions to illicit insights on experience and future recommendations. Twelve participants registered to attend focus groups, however, only two caregivers were able to complete a focus group.

Qualitative and quantitative data were analyzed separately and then merged.^{6,7} Quantitative survey *data* were analyzed using one-way analysis of variance tests (or non-parametric equivalent) to determine differences among subgroups of participants. Paired sample t-tests were used to explore the quantitative data on caregiver knowledge, attitude, preparedness and self-efficacy. Qualitative focus group data and open-ended *after-training* questionnaire responses were analyzed to generate categories that capture the experience of the training through content analysis.⁸

What did we find?

The majority of the participants were either the child (33%) or spouse (34%) of a PLWD. Seventy-five percent of participants were women (75%); and 57% were 55 or older. Eighty percent of participants graduated from post-secondary education, and 66% reported they did not have difficulty paying their bills at the end of the month. Twelve (16%) participants identified as a visible minority, half of which identified as a First Nations, Inuit, or Métis person.

Engagement with the content of the learning resource was reported by *after-training* questionnaire respondents (n=25). Fifty-two percent only completed five lessons or less.

For the twenty-five participants who completed the *after-training* questionnaire, **IncludeMe™** led to participants on average feeling more prepared for caregiving and more confident to respond to disruptive behaviours. These modest improvements were most evident in participants who identified as women. No significant changes in knowledge, attitude, or confidence in obtaining respite were observed.

Although many participants expressed satisfaction with **IncludeMe™**'s easily digestible approach to education, the learning resource's acceptability was low. Some participants indicated that the content offered a limited amount of new information, while others brought attention to frustrations with the user-interface.

What are the next steps?

Through our evaluation of the development and impact of **IncludeMe™ A Starting Point for Dementia Caregivers**, we made several recommendations for future adaptations of the learning resource before its scale and spread. These include:

1. Engagement with diverse caregiver experts-by-experience to ensure curriculum is relevant and meets the educational needs of the target audience;
2. Increase ease of use by considering how to design the learning management system to improve user experience, which may increase the amount of the training people complete and improve the overall impact of **IncludeMe™**; and

3. improve compatibility between **IncludeMe™** and target audience by a) using recruitment methods to reach caregivers earlier in their journey before crisis who have a higher need for knowledge of person-centred dementia care, or b) purposefully targeting new caregivers within the broader circle of care.

Iris the Dragon intends on acquiring additional funding to update **IncludeMe™** based on the recommendations.

How is this research funded and supported?

This work was funded by the Public Health Agency of Canada's Dementia Strategic Fund.

To learn more about this work

To learn more about **IncludeMe™ A Starting Point for Dementia Caregivers** follow the QR code.



To cite this work

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References

