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IncludeMe™ - A Starting Point for Dementia Caregivers: Evaluation of the Pilot Learning Resource

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Prepared by
Celina Carter RN PhD | Research Scientist, SE Research Centre
Ryan McLeod MA | Research Associate, SE Research Centre

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For permission of information, please contact the SE Research Centre:
SE Research Centre
90 Allstate Parkway, Suite 800
Markham, ON L3R 6H3
research@sehc.com
research.sehc.com

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research.sehc.com
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Executive Summary

In support of the unique educational needs of new caregivers of people living with dementia (PLWD) living in rural communities, Iris the Dragon, in collaboration with project co-lead Addiev Corporate Training, developed a learning resource called 'IncludeMe™ - A Starting Point for Dementia Caregivers' – an online gamified, scenario-based resource that aims to improve the knowledge, skill, and attitude for new caregivers of PLWD or persons showing signs of dementia. The pilot of the newly developed learning resource uses a 'choose your own adventure' design, that allows users to navigate the training to prioritize the lessons that are most important to them. The learning objectives of IncludeMe™ are:

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 person living with dementia;
3) Preparing a care plan, plus a circle of relational care for the person living with dementia; and
4) Develop a plan for personal self-care and social connectedness.

The pilot of IncludeMe™ was evaluated by an evaluation team from the SE Research Centre to understand the effectiveness and impact on people using IncludeMe™, and provide insights to support its refinement, scale and spread. In this report the SE Research Centre team describes the evaluation methods and reports findings on, participation; engagement with IncludeMe™; the impact of the training on participants' knowledge, attitude and perception of skills; and IncludeMe™'s usability, inclusiveness, and acceptability.

The mixed-methods approach to the evaluation of IncludeMe™ involved: 1) collecting before training (T1) survey data (n=76); 2) providing participants access to IncludeMe™ for 30 days; 3) collecting after training (T2) survey data 30 days later, which included both scaled questions (n=25) and open-ended questions (n=14); and 4) hosting a focus group (n=2). The before (T1) and after (T2) training surveys used psychometrically tested scales to measure participants' 1) attitudes towards PLWD, 2) knowledge of person-centred dementia care, 3) self-efficacy to obtain respite, 4) self-efficacy to respond to disruptive behaviours, and 5) preparedness for caregiving. The focus group facilitated discussion on the perceived impacts of the training as well as the perceived inclusiveness, usability, and acceptability of IncludeMe™.

Of those who completed the after training (T2) survey (n=25), most completed less than half of the lessons. Findings suggest that for this sample, IncludeMe™ led to modest improvements in preparedness for caregiving and self-rated confidence to respond to disruptive behaviours.

These improvements are in alignment with areas for improvement identified in the before training (T1) survey, most evident in participants identifying as women. The content and delivery did not result in significant changes in knowledge, attitude, or confidence in obtaining respite.

Regarding IncludeMe™'s usability, inclusiveness, and acceptability, many participants found the training promoted ease of learning stating they "enjoyed the program" and it was "very helpful". Some participants explained they were satisfied because they found the training improved their knowledge by offering information in a way that was easy to learn. Most participants found the training somewhat inclusive, however one participant commented on a need for a wider range of caregiving roles and relationships to be reflected in the scenarios. Acceptability was a challenge for many. For some, this was because the content was not new and for some because of difficulties navigating the 'choose your own adventure' design and glitches and frustrations with the user-interface (e.g., signing-in, tracking progress, slow animations).

Several challenges became evident during the evaluation of this project, particularly related to low levels of engagement resulting in minimum samples sizes not being met for either the quantitative or qualitative data, making it less possible to offer a robust and generalizable evaluation of the training. To better understand the conditions that contributed to this challenge the SE Research Centre team held a project partners debrief session, which highlighted learnings about external factors, compatibility between the learning resource characteristics with the target audience, and the design, which may explicate the low levels of engagement with the target audience.

From this evaluation and the project partners debrief session there are two important takeaways to guide future adaptations of IncludeMe™:

1) increasing ease of use by considering how to design the learning management system to improve user experience may increase the amount of the training people complete and improve the overall impact of IncludeMe™, and
2) improving 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.

These approaches may improve the level of engagement by the target audience.

IncludeMe™ - A Starting Point for Dementia Caregivers: Evaluation of the Pilot Learning Resource

April 30, 2024
Celina Carter *RN PhD*
Ryan McLeod *MA*

1. Background and Rationale

There has been a growing shift away from institutional forms of care for Canadians with chronic health conditions or aging needs to an increased reliance on care within the home (Mah et al., 2021). Caregivers are essential to ensuring effective health care support and good health management, particularly for those wishing to age in the place where they live. In Ontario, an estimated 3.3 million Ontarians, 29% of the provincial population, are caregivers. According to Statistics Canada (2018), approximately one in four Canadians aged 15 and older (or 7.8 million people) provide care to a family member or friend with a long-term health condition, a physical or mental disability, cognitive decline, and/or problems related to aging. Caregivers are the parents of young children, mature children of aging parents, elderly parents of mature children, and life-long partners or friends (Mah et al., 2021). They are largely unseen and unsung, often giving themselves to the role of caring 24/7 and to the end (Aledeh & Adam, 2020).

Many caregivers would benefit from more support, including the caregivers of people living with dementia (PLWD) (Sztramko et al., 2021). Currently, it is estimated that 600,000 people in Canada are living with dementia, and by 2030, this number is projected to grow to 1 million (Alzheimer Society of Canada, 2022). Many people caring for PLWD feel ill prepared, uninformed about dementia, unsure where to turn to for help, and misunderstood (Sztramko et al., 2021). Furthermore, with these caregivers being at an increased risk for depression, anxiety, declining physical health, and financial stress there is a need for accessible and acceptable supportive resources (Bressan et al., 2020; Sztramko et al., 2021).

Across the spectrum of caregivers of PLWD certain needs have been identified including: 1) being supported (e.g., social support and formal care services), 2) receiving accessible and personalized information (e.g., knowledge about dementia and care services), 3) being trained and educated to care for the PLWD (e.g., coping skills and caring skills), and 4) finding a balance between caring duties and own needs (Bressan et al., 2020). Less is known about new or early-stage caregivers to PLWD, however there is evidence they have unique stage-specific needs (Boots et al., 2015). Many new caregivers have not accepted their situation due to stigma and not wanting to appear as needing professional help, yet many are struggling and finding it difficult to cope (Boots, et al., 2015). To better support these new caregivers, resources can aim to facilitate acceptance, provide disease specific knowledge to help them navigate changes in behaviour of the PLWD, promote taking a break, and provide information on how to adapt and make plans for future care (Boots et al., 2015).

The Alzheimer Society of Lanark Leeds Grenville in Ontario noted gaps in accessibility as well as gaps in services particularly in reaching and supporting new caregivers of PLWD in their rural area with limited community resources. The Alzheimer Society of Lanark Leeds Grenville wanted to support the development of an online caregiver learning resource offered asynchronously to new caregivers. Previous educational initiatives for caregivers of PLWD that promote disease-specific knowledge and how to navigate the caregiving role can lead to a reduction in distress, increased quality of life for caregivers (Sztramko et al., 2021), and increased confidence and understanding (Morgan et al., 2014). Internet-based education interventions for family caregivers of PLWD are acceptable to caregivers and can be effective in improving well-being, self-efficacy, confidence, and skills for caregiving as well as reducing depressive symptoms, anxiety, and perceived burden of caregiving (Ottaviani et al., 2022). However, few online learning resources have been designed for, or tested with new caregivers for PLWD (Boots et al., 2017; Ottaviani et al., 2022).

Iris the Dragon, an organization specializing in using story to deliver psycho-education to caregivers partnered with Addiev Corporate Training to develop a learning resource called IncludeMe™ - A Starting Point for Dementia Caregivers (referred to as IncludeMe™ throughout this report), which is an online gamified, scenario-based resource that aims to improve the knowledge, skill, and attitude for new caregivers of PLWD or persons showing signs of dementia (Carter & McLeod, 2024). The resource focuses on caregiver learnings in four areas:

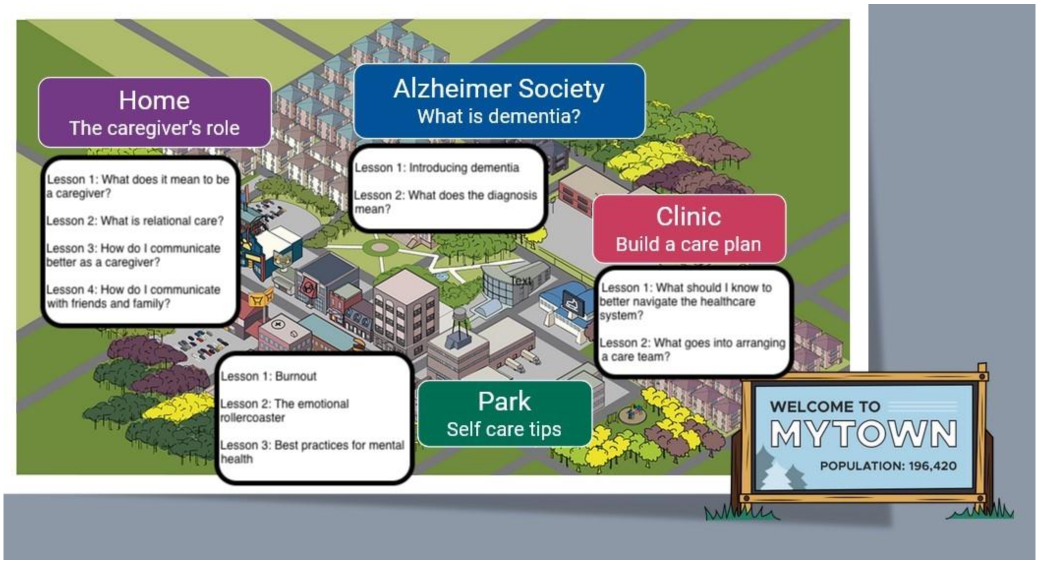
1) Knowledge about dementia including the correct terminology to communicate to others about the condition;
2) Navigating the healthcare system and local community supports to initiate a circle of relational care for the person living with dementia;
3) Preparing a care plan, plus a circle of relational care for the person living with dementia; and
4) Develop a plan for personal self-care and social connectedness.

The final version of the evaluation-ready pilot of IncludeMe™ consists of four modules with two to four lessons in each module. The learning resource is designed to allow people to navigate the training in a 'choose your own adventure' format. The outline of the pilot of IncludeMe™ consists of the following modules with corresponding lessons:

1. Home: The caregiver's role
    - Lesson 1: What does it mean to be a caregiver?
    - Lesson 2: What is relational care?

  - Lesson 3: How do I communicate better as a caregiver?
  - Lesson 4: How do I communicate with friends and family?
2. Alzheimer Society: What is dementia?
  - Lesson 1: Introducing dementia
  - Lesson 2: What does the diagnosis mean?
3. Clinic: Build a care plan
  - Lesson 1: What should I know to better navigate the healthcare system?
  - Lesson 2: What goes into arranging a care team?
4. Park: Self care tips
  - Lesson 1: Burnout
  - Lesson 2: The emotional rollercoaster
  - Lesson 3: Best practices for mental health

Outline of the IncludeMe™ Pilot



2. Evaluation Objectives

The SE Research Centre's role was to evaluate the pilot of IncludeMe™. The objective of the evaluation was to understand the effectiveness and impact on people using IncludeMe™ and provide insights to support its refinement, scale, and spread. Two research questions guided the evaluation:

1. How does participating in the training impact caregiver's:
   a) attitudes towards dementia;
   b) preparedness for caregiving;
   c) knowledge of dementia; and
   d) self-efficacy?

2. To what degree do participants find the training: a) inclusive; b) usable; and c) acceptable?

3. Methods

3.1 Study Design

This evaluation study used a mixed-methods convergent design to address the two evaluation questions for a more comprehensive understanding of the effectiveness of the training than using a single method of evaluation (Doyle, Brady, & Byrne, 2016; Grant & Giddings, 2002).

3.2 Study Site

The study site was the Lanark Leeds Grenville region in Ontario, Canada. This region was chosen because according to the Alzheimer Society of Lanark Leeds Grenville, 1) there is a high need for caregiver support with one in five people having experience caring for a PLWD, and 2) there are currently no online asynchronous educational learning resources for new caregivers of PLWD in this region. When planning recruitment, the decision was made to recruit Ontario wide so as not to exclude people who had recently moved out of the target region.

3.3 Participants

The following participants were included in the evaluation: caregivers (e.g., a family member, friend, neighbour, or other community member) of a PLWD or of a person showing signs of dementia who:

1) Have newly taken on this caregiving role (caregiving for 0-5 years),
2) Want to learn online and/or were looking for learning resources that are more accessible and are open to learning online;
3) Have access to the internet and a device to use the learning resource;
4) Are over 18 years of age; and
5) Live within Ontario (to not exclude those who have recently moved out of the target region).

3.4 Sample Size

The target for a representative sample of the 16,500 adult caregivers of PLWD from the Lanark Leeds Grenville region for the quantitative portion of this evaluation was 163 participants with a confidence level of 80% and a margin of error of 5%. The target sample size for the qualitative portion of this evaluation was 10-20 participants (Patton, 2002).

3.5 Recruitment and Remuneration

To meet project deadlines, recruitment occurred over a three-month period between December 2023 – March 2024. Recruitment was led by Iris the Dragon and Addiev Corporate Training, the co-leading partners responsible for creating the IncludeMe™. Recruitment happened in close collaboration with the Alzheimer Society of Lanark Leeds Grenville, which has established relationships in the community with PLWD and their caregivers totalling over 4,000 people. Eligible participants were recruited through existing channels including in person visits and day programing, direct mail, email, web and social media, newsletters, and community events. Additionally, the recruitment fly was shared on the SE Research Centre Community List, the Alzheimer Society Research Portal; and the Ontario Caregiver Organization – External Opportunities website.

Participant remuneration consisted of 1) before (T1) and after (T2) training surveys - individuals who completed either survey were given the option to enter their email in a draw to receive one of five $50.00 CAD e-gift cards; and 2) focus groups – individuals who completed a focus group were given the option of receiving a $50.00 CAD e-gift card.

3.6 Data Collection

The data collection plan included before (T1) and after (T2) training surveys collected via the online secure platform Qualtrics (https://www.qualtrics.com) and three online focus groups conducted over video conferencing software. The before training (T1) survey (see Appendix A) data was to be collected first. Participants would then be provided access to IncludeMe™ for 30 days. After 30 days, participants would be sent a link to the after training (T2) survey (see Appendix B). Participants would then be invited to attend one of three online focus groups (see Study Design in Table 1).

Table 1: Study Design

Recruitment period	***Rolling recruitment for 3 months***			
Timeline for data collection	Day 0	Day 0-30	Day 30-60	Day 30-60
Data collection	Demographic form and before (T1) training survey	Training done within a 30-day window	After (T2) training survey	Focus groups

Before (T1) and After (T2) Training Surveys

Before training (T1), participants were invited to complete:

1) demographics questions to support analysis of how gender, being a visible minority, income, etc., impact the outcomes of this training (Canadian Institutes of Health Research, 2022); and
2) three psychometrically sound instruments (see information on measurement scales in Appendix C) for use with caregivers of PLWD to evaluate:

  a. caregiver preparedness using Archbold et al.'s (1990) 8-item, 5-point Likert scale, Preparedness for Caregiving Scale (α ≥0.9) (Henriksson et al., 2012);
  b. caregiver self-efficacy using two of the three subscales from Steffen et al.'s (2002) Revised Scale for Caregiving Self-Efficacy (α ≥0.79) (Steffen et al., 2019);
  c. attitude towards caregiving for PLWD as well as knowledge of person-centred care using the 6-item, 7-point Likert scale, Dementia Attitudes Scale (DAS-6) (α ≥0.83) (Clark et al., 2023).

After training (T2), participants were invited to complete:

1) a question about how much of the training they completed;
2) the three psychometrically sound instruments listed above;
3) five scaled questions about IncludeMe™'s usability (e.g., satisfaction, ease of use, ease of learning), inclusiveness (e.g., familiarity), and acceptability (e.g., usefulness) which were created for this survey; and
4) an open-ended question about recommendations for improving IncludeMe™.

Focus Groups with Caregivers of PLWD

After using of IncludeMe™ for 30 days, participants were invited to attend one of three focus groups to understand participant's experience of the training (Freeman, 2006; Grant & Giddings, 2002). Focus group participants were invited to discuss their experience of: 1) preparedness, self-efficacy, and attitudes towards caregiving for PLWD after using IncludeMe™ to illuminate the survey findings, and 2) inclusiveness, usability, and acceptability of IncludeMe™.

3.7 Data Analysis

Qualitative and quantitative data were analyzed separately and then merged (Creswell & Plano Clark, 2011; Doyle, Brady, & Byrne, 2016). *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 to respond to disruptive behaviours and obtain respite. *Qualitative focus group data* were transcribed verbatim and categories that capture the experience of the training were generated through content analysis (Elo & Kyngäs, 2008). The same analytical approach was used for the open-ended T2 survey responses.

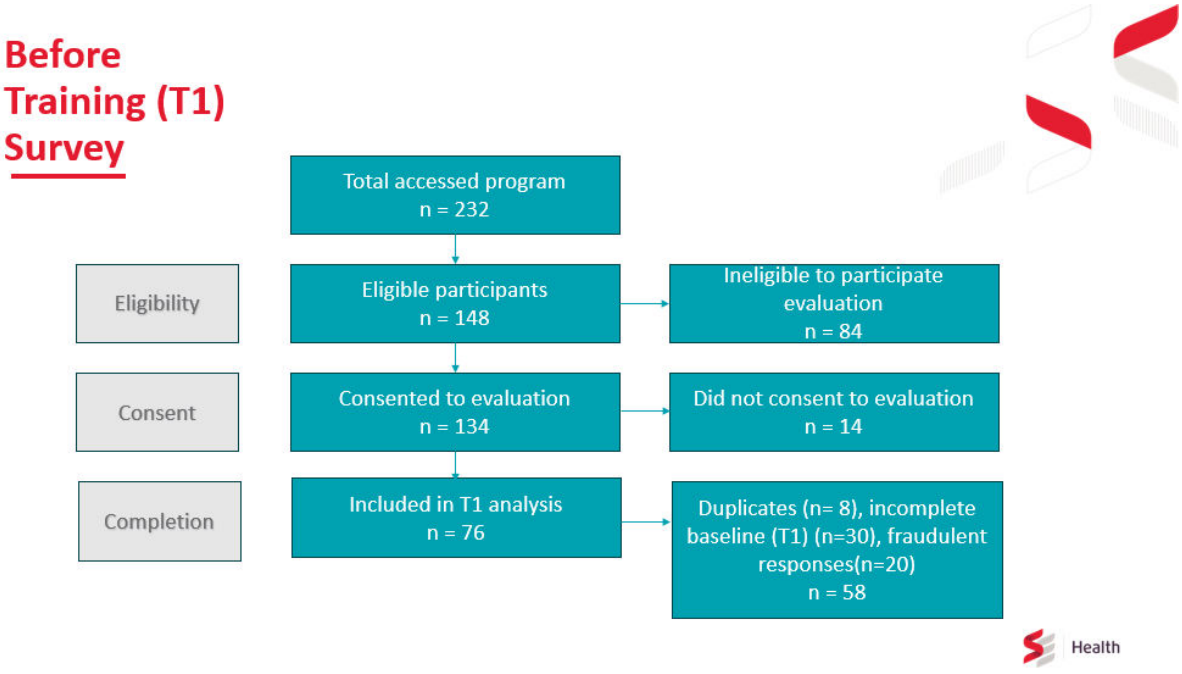
4. Findings

4.1 Whom did we Reach?

Of the 232 individuals who accessed the before training (T1) survey embedded in IncludeMe™, 84 individuals did not meet the eligibility criteria, 14 did not consent to the evaluation, 30 did not complete T1, 20 were removed due to fraudulent responses (i.e., multiple entries linked to a single IP address), and 8 accessed the survey multiple times (see Figure 1). The remaining 76 survey responses were included in the analysis of before training data. Twenty-five of the 76 participants completed both the before (T1) and after (T2) training surveys.

Twelve people registered to attend focus groups, however, only three caregivers were able to attend. One caregiver had technical difficulties and left, resulting in only two participants in one focus group. The after training (T2) survey data included 14 open-ended responses describing recommendations to improve IncludeMe™. The findings of this evaluation are not generalizable due to the minimum sample sizes for both the quantitative (n=163) and qualitative (n=15) data not being met. This resulted in an insufficient amount of qualitative data to use for triangulation, making it less possible to offer a robust evaluation of IncludeMe™ (Doyle, Brady, & Byrne, 2016) (see 6. Project Partner Reflections on the Results of the Project section).

Figure 1: Participation in Before Training (T1) survey



4.2 Demographics – Who were the Participants?

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 being in a visible minority, half of which identified as a First Nation, Inuit, or Métis person (see Table 2).

Of the 76 participants who completed T1, 39% lived in rural areas, 29% lived in urban areas, and 32% lived in metropolitan areas. Although IncludeMe™ was intended to address the needs of caregivers in rural areas with limited resources, over half of the sample were from urban or metropolitan areas.

Table 2: Participants Demographic Data (n=76)

Variable		Before (T1) Training N (%)	After (T2) Training N (%)
Area of Residence	Rural	29 (38.2)	7 (28)
	Urban	22 (28.9)	9 (36)
	Metropolitan	25 (32.0)	9 (36)
Relationship	Spouse	26 (34.2)	12 (48)
	Child	25 (32.9)	7 (28)
	Sibling	4 (5.3)	2 (8)
	Grandchild	5 (6.6)	0 (0)
	Other	16 (21.1)	4 (16)
Age	25 -34	8 (10.5)	3 (12)
	35 – 44	11 (14.5)	3 (12)
	45 - 54	14 (18.4)	2 (8)
	55 - 64	17 (22.4)	6 (24)
	65 or older	26 (34.2)	11 (44)
Gender	Woman	57 (75)	17 (68)
	Man	18 (23.7	7 (28)
	Prefer not to answer	1 (1.3)	1 (4)
Visible Minority	No	62 (81.6)	19 (76)
	Yes	12 (15.8)	4 (16)
	Prefer not to answer	2 (2.6)	2 (8)
First Nation, Inuit, Metis	No	67 (88.2)	21 (84)
	Yes	6 (7.9)	3 (12)
	Prefer not to answer	3 (3.9)	1 (4)
Education	High school degree or equivalent	2 (2.6)	2 (8)
	Some college or university but no degree	13 (17.1)	4 (16)

	Associate degree	16 (21.1)	5 (20)
	Bachelor degree	27 (35.5)	7 (28)
	Graduate degree	18 (23.7)	7 (28)
Experiencing Income insecurity	No	50 (65.8)	18 (72)
	yes	22 (28.9)	6 (24)
	Prefer not to answer	4 (5.3)	1 (4)

4.3 Participant Attitude, Preparedness, and Self-Efficacy before using IncludeMe™

The average T1 scores of the 76 participants are displayed in Table 3. Before the training, the average (mean) score on the DAS-6 attitude towards PLWD subscale was 4.99 out of 7 (standard deviation [SD]=1.33) and 5.40 out of 7 (SD=1.15) on the DAS-6 knowledge of person-centred dementia care subscale, indicating more positive knowledge than attitude.

On the Revised Scale for Caregiving Self-Efficacy, the average (mean) score on self-efficacy in obtaining respite subscale was 54.39 out of 100 (SD=22.61) and the average (mean) score on self-efficacy responding to disruptive behaviours subscale was 64.58 out of 100 (SD=20.04). These scores indicate “moderate” confidence on both subscales with participants being more confident responding to disruptive behaviours than obtaining respite. The average (mean) score on the Preparedness for Caregiving Scale was 16.76 out of 32 (SD=5.82), which reflects participants not feeling well prepared.

Participants who identified as women had statistically significant lower scores on self-efficacy in obtaining respite (Mean [M]=50.49 +/- 22.89) and preparedness for caregiving (M=15.96 +/- 22.98) compared to participants who identified as men or preferred not to answer (M=66.1 +/- 17.25; 19.16 +/- 5.35), t(74)=-2.72, p=0.008; t(74)=-2.12, p=0.019).

4.4 Engagement with IncludeMe™

Engagement with the content of the learning resource was reported by T2 survey respondents (n=25). Forty-eight percent completed six or more lessons. Due to the design of the learning management system as a ‘choose your own adventure’ training, it was not possible to generate data about use or attrition rates using metrics from user behaviour on IncludeMe™.

4.5 Changes after taking IncludeMe™

Twenty-five participants completed both before (T1) and after (T2) training surveys; these cases were included in the analysis of changes in outcomes after taking IncludeMe™. For these respondents, but not generalizable across the population of caregivers in the region, there were statistically significant differences in the mean score on the Preparedness for Caregiving Scale (t(24)=2.447, p=0.022) and the responding to disruptive behaviours subscale of the Revised Scale for Self-efficacy (t(24)=2.324, p=0.0290) after taking IncludeMe™. On average, participants scores were 2.48 points higher on the Preparedness for Caregiving Scale (95%

confident interval [CI] [0.28, 4.57]) and 5.5 points higher on the responding to disruptive behaviors subscale (95% CI [0.62, 10.42]), reflecting modest improvements to preparedness and the confidence to positively responding to disruptive behaviors.

Table 3: Average Participant Scores Before and After IncludeMe™

Measure	Outcome	Mean before IncludeMe™ (n=76)	Mean after IncludeMe™ (n=25)	P value
Dementia Attitudes Scale (DAS) – 6	Attitude towards PLWD (e.g., social comfort)	4.99 (SD=1.33)	5.03 (SD=1.04)	0.223
Dementia Attitudes Scale (DAS) – 6	Knowledge of person-centred dementia care	5.40 (SD=1.15)	5.35 (SD=1.00)	0.439
Revised Scale for Caregiving Self-Efficacy	Self-Efficacy: Obtaining Respite	54.39 (SD=22.61)	52.32 (SD=19.85)	0.701
Revised Scale for Caregiving Self-Efficacy	Self-Efficacy: Responding to Disruptive Behaviours	**64.58** (SD=20.04)	**66.00** (SD=18.13)	**0.029****
Preparedness for Caregiving Scale	Preparedness	**16.76** (SD=5.82)	**19.52** (SD=5.54)	**0.022****

One of the two focus group participants shared how the training helped them feel more prepared:

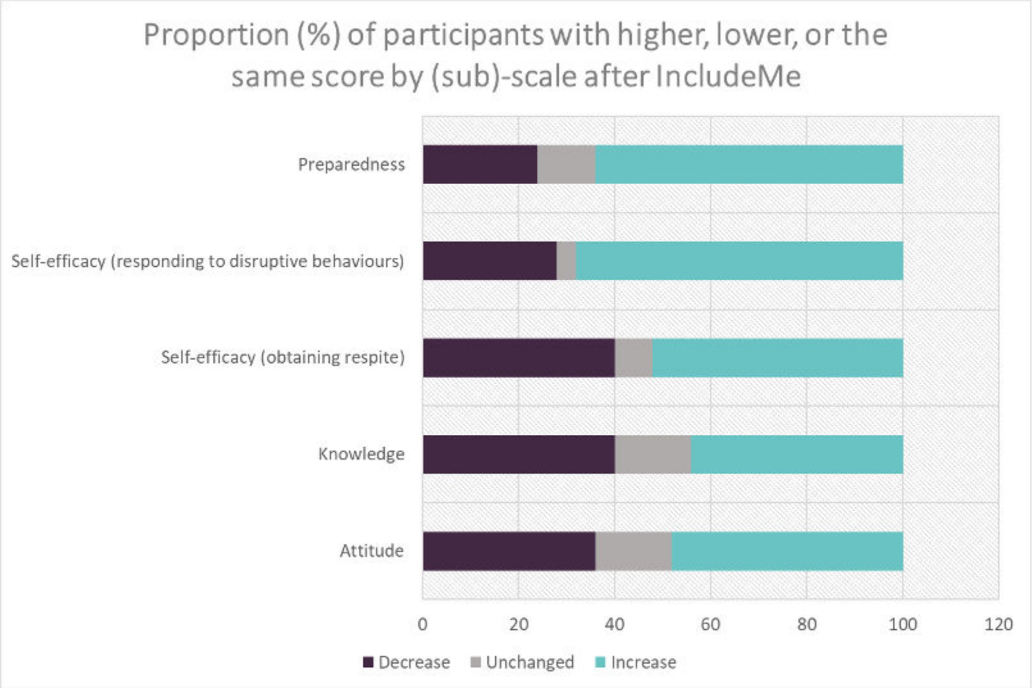
> "it really helped me to prepare a lot about, because … what I gained is not just about understanding the medical condition or knowledge about the condition. It also extended on how I can provide emotional support for the patient." - Focus group participant

While neither focus group participant explicitly discussed feeling more confident positively responding to disruptive behaviours, one of the 14 participants who provided recommendations on the T2 survey shared they were more aware of their need for support obtaining respite:

> "Caregiving for a PLWD changes depending on the day … [I] have to learn to take time for myself and to learn to deal with the frustration on a daily basis. And to let friends and family know that I may need their help" – T2 survey response

Figure 2 shows the proportions of changes on knowledge, attitude, preparedness, and self-efficacy to obtain respite and respond to disruptive behaviors (i.e., the number and percentage of participants (n=25) whose scores increased, decreased or were unchanged). Noticeably, self-confidence in obtaining respite, self-confidence responding to disruptive behaviors, and preparedness for caregiving increased in over half of evaluation participants.

Figure 2: Proportion of Participants with Higher, Lower or the Same Score in each of the Measurement Scales Used (n=25)



4.6 Satisfaction with IncludeMe™: Usability, Inclusiveness, and Acceptability

To provide insight into participants' experience of IncludeMe™'s usability (e.g., satisfaction, ease of use, ease of learning), inclusiveness (e.g., familiarity), and acceptability (e.g., usefulness), we drew on three sources of data, 1) the five scaled questions in the after training (T2) survey (n=25); the open-ended responses about recommendations in the after training (T2) survey (n=14) and focus group responses (n=2). Based on data from the scaled questions (see Table 4), the overall average experience of the training was rated as 'fair', that is between 'poor' and 'good'. Participants stated they "enjoyed the program" and it was "very helpful". Some participants explained they were satisfied because they found the training improved their knowledge by offering information in a way that was easy to learn. Two participants commented:

> "I'll say it's really, really helped me improve my knowledge though I had a little bit of experience, but it was not enough. ... it really, really helped me improve my knowledge. I got to understand things I didn't really understand. And one thing I also love about the program is that it's not so complex ... Even someone that doesn't have the knowledge or

> someone that does not know anything about this can easily go through it and understand what it's trying to say" - Focus group participant 1
>
> "…providing more knowledge, widening my insights about and all that, so it was very helpful. And on the aspect of how concise it is, it was very direct to the point, straightforward" - Focus group participant 2

In contrast, two participants suggested ease of learning may be improved by shortening the time it takes to go through the animation dialog in the scenarios. They stated:

> "I found that clicking through the scenarios had both advantages and disadvantages. It kept my interest exploring the map and so forth, but I got impatient with the dialog at times" - T2 survey response
>
> "…the animations were slow to progress and annoying in that they required you to press a button after every sentence spoken. I would prefer this information in a video clip that advances on its own, with the option of reading the content in text available too" - T2 survey response

Ease of use was noted as a challenge by some participants, with the overall average experience of exploring and navigating the training rated as 'neutral', that is, in between 'very difficult' and 'easy to use'. Participants explained there were issues with the user-interface that shaped user experience of IncludeMe™ as captured by these quotes:

> "Design it so repeated log ins and registrations are not required each time, have it keep track accurately of how much has been completed by a user - and allow [a] user to resume where they left off" - T2 survey response
>
> "I did have issues trying to save the sessions and move to the next. Had to redo them about 3 times. That was frustrating. But I got over it and did finish" - T2 survey response
>
> "I also found the set up of navigation pretty clunky and too many layered steps" - T2 survey response

There were several recommendations for improving the glitches and frustrations with the user-interface that impact user experience of IncludeMe™: a) allowing for repeat log-ins, b) making the table of contents more prominent, c) upgrading the interface to be less "clunky" with less information, d) making sure progress is accurately tracked through the training – for many the progress stayed at 0%, e) providing video clips instead of animations, which were slow and cumbersome, f) making it easier to access resources using simple text documents and adding more resources, and g) offering an audio reader.

On average participants found the challenges portrayed in the training were 'somewhat familiar', that is, in between 'slightly familiar' and 'moderately familiar'. One participant commented the challenges did not match their experience as a caregiver, stating: “Scenarios seem also mostly based on someone caregiving directly and not for someone who doesn't live with the PLWD but is their power of attorney”. However, other participants shared they could see themselves in the scenarios and thought the storylines were effective and inclusive of their experience. They stated:

> “I could see myself in these. I was like, this is what I was going through and this is really what I needed. This is the help I needed. This is the assistance I needed, this is the knowledge I needed for this kind of thing” - Focus group participant 1

> “One thing I actually like about the training was the aspect of the videos. It was very creative … was my favourite part because it was very important and the stories on those videos I felt fitted in and it was very effective” - Focus group participant 2

Regarding acceptability, the usefulness of the training was rated as ‘neutral’, that is, in between ‘slightly useful’ and ‘useful’, and participants were ‘not sure’ they would use the tips, tools, or resources, which is, in between ‘unlikely’ and ‘likely’. One reason was because the information was not new to some participants. Two elaborated:

> “I found the information very basic, therefore did not gain much” - T2 survey response

> “I learned a few tips but mostly feel I am already doing almost everything that was covered” - T2 survey response

These quotes align with the before training (T1) data that demonstrated participants entered the training with some positive knowledge of person-centred dementia care. Building on this, there were many requests for more resources when asked how to improve IncludeMe™. In contrast, another participant explained the training was useful in helping them learn what to do to cope with being a caregiver, stating the program was “very helpful”.

Table 4: T2 Usability, Inclusiveness, and Acceptability Questions

T2 Usability, inclusiveness, and acceptability questions	Mean (n=25)	Min	Max
Overall, how was your experience using the training program? (1 Very poor; 2 Poor; 3 Fair; 4 Good; 5 Very good)	3.48	1	5
Overall, how was your experience exploring and navigating the training program? (1 Very difficult; 2 Difficult; 3 Neutral; 4 Easy; 5 Very easy)	3.36	1	5
Overall, how familiar do the challenges portrayed in the training program feel to you? (1 Not familiar at all; 2 Slightly familiar; 3 Somewhat familiar; 4 Moderately familiar; 5 Extremely familiar)	3.88	2	5
Overall, how likely are you to use the tips, tools, and resources from the training program in your role as a caregiver?	3.84	2	5

(1 Very unlikely; 2 Unlikely; 3 Not sure; 4 Likely; 5 Extremely likely)			
Overall, how useful is the training program to meeting your educational needs as a caregiver? (1 Not useful at all; 2 Slightly useful; 3 Neutral; 4 Useful; 5 Very useful)	3.6	2	5

5. Discussion of Study Results

New or early-stage caregivers to PLWD have unique stage-specific needs, with many not accepting their situation yet struggling, and finding it difficult to cope (Boots et al., 2015). IncludeMe™ was created to provide stage-specific, interactive, and informative information to improve the knowledge, skill, and attitude for new caregivers of PLWD or people showing signs of dementia.

Recruitment efforts were led by Iris the Dragon and Addiev Corporate Training, the co-leading partners responsible for creating IncludeMe™, in close collaboration with the Alzheimer Society of Lanark Leeds Grenville. Recruitment efforts resulted in 76 new caregivers completing before training (T1) surveys. Twenty-five participants (33%) completed the after training (T2) survey. Twelve people registered to attend focus groups, however, only two participated in one focus group. These findings indicate there is some interest in IncludeMe™, however reaching new caregivers and keeping them engaged remains a challenge (Boots et al., 2015; Boots et al., 2017).

From before (T1) training data (n=76), we know that participants felt unprepared for their caregiving role with moderate confidence in obtaining respite and responding to disruptive behaviours, and some positive knowledge of person-centred dementia, and a slightly less positive attitude towards PLWD. Notably, women caregivers felt the least prepared and had lower confidence obtaining respite compared to participants who identified as men or preferred not to answer. From the after training (T2) data (n=25), we know that most participants completed less than half of the lessons in IncludeMe™. Based on the before (T1) and after (T2) survey results, the impact of IncludeMe™ was increased feelings of preparedness for caregiving and increased confidence in responding to disruptive behaviours. The content and delivery did not result in significant changes in knowledge, attitude, or confidence obtaining respite.

In examining the effectiveness and impact of IncludeMe™ among the limited sample of those who engaged with the learning resource there are four important insights to highlight: 1) new caregivers accessing IncludeMe™ were primarily women, older than the age of 55, and not living in rural areas – leaving room to target other diverse groups of new caregivers in the future; 2) women were more likely to feel unprepared for caregiving responsibilities and less confident to obtain respite – indicating a potential need for support, which could benefit from targeted resources, 3) IncludeMe™, on average, led to modest improvement in preparedness for caregiving and self-rated confidence to respond to disruptive behaviours - though these results are not generalizable to the population they are promising; and 4) IncludeMe™ did not result in any significant changes in participants' knowledge, attitudes, or self-confidence to obtain respite – which could be due to a variety of factors (e.g., ease of use, content, amount of training completed) that require further exploration.

From the data on participants' experience of IncludeMe™'s usability, inclusiveness, and acceptability we can highlight three important insights for consideration: 1) to improve usability there are several recommendations to improve ease of use such as allowing multiple sign-ins, accurately tracking progress, and upgrading the user interface, 2) including challenges familiar to a wider range of caregiving roles and relationships could improve inclusiveness, and 3) acceptability appears to be related to previous knowledge held by caregivers and therefore targeting the rollout of IncludeMe™ to those who feel less knowledgeable could improve acceptability.

6. Project Partner Reflections on the Results of the Project

Several challenges became evident during the evaluation of this project, particularly related to low levels of engagement resulting in minimum samples sizes not being met for either the quantitative or qualitative data, limiting the possibility of generating significant and generalizable findings. To better understand the conditions that contributed to this challenge, the SE Research Centre team held a project partners debrief session involving a family caregiver expert-by-experience and representatives from Iris the Dragon, Addiev Corporate Training, and the Alzheimer Society of Lanark Leeds Grenville. The results of this debrief are presented here.

External factors: Project partners discussed two unanticipated issues that arose during the development and evaluation of this project, a) a shortened project window, and b) the time of year for recruiting participants. Representatives from the project partner organizations Addiev Corporate Training and the Alzheimer Society of Lanark Leeds Grenville explained that due to the limited time to develop and evaluate the project, there was not enough time to recruit the participants they anticipated:

> "when the project started up, … we were already sort of two months into the project before project approval and funding came through. So we had a much shorter window to operate with. … so time was a constraint that I think contributed to us not quite getting our numbers"

> "We have quite a few caregivers in our roster. However, they've all been through education or support in some aspect with us … so we get new people all the time

> through [the] … Care navigator … We would probably get in a month … for her new recruitments … maybe 30-40 people”

With recruitment only running for three months, it was not possible for the Alzheimer Society of Lanark Leeds Grenville, the partner primarily responsible for recruitment, to recruit the minimum sample. The time of year for recruitment, particularly December and January were also discussed as a time when many caregivers are not available due to other life activities. January is also Alzheimer’s awareness month with lots of information being sent to caregivers, which may have overshadowed recruitment efforts.

Compatibility of IncludeMe™ with target audience: Project partners raised questions about the fit of IncludeMe™ for meeting the needs of the target audience due to challenges related to a) the source of information drawn on to develop content, b) ability of the training to address the target audience’s needs, and c) the relative priority of the training to competing needs of the target audience, all of which might help to account for low levels of engagement.

In assessing the range of perspectives engaged in generating the content of IncludeMe™ from a Gender Based Analysis (GBA+) analysis framework (Government of Canada, 2022), we found that partners with lived experience and perspectives of caregivers from equity-deserving groups, including racial and ethnic minorities and diverse gender identities were limited (Carter & McLeod, 2024). Additionally, only one partner had lived experience as a new caregiver to a PLWD. This limitation was echoed by one project partner representative who reflected, “Do we understand who new caregivers are? And how to reach them? Maybe not”. Developing content without a clear understanding of the diverse needs of the target audience may have led to lower levels of participation and engagement with IncludeMe™.

The hypothesis for this project was that an online learning resource would increase access to resources for new caregivers to support their need for improved knowledge, skill, and attitude. However, seeing the low engagement with the evaluation, the partner organizations reflected that by the time new caregivers are looking for resources, in many cases they are in crisis and desire respite and more direct support than an asynchronous learning resource can provide. A representative from the project partner organization Addiev Corporate Training who is also a new caregiver explained:

> “I needed that [in-person education] because I know my personal experience at that time of crisis, I couldn't absorb any information. So, I sat down with a social worker and she walked it through. I don't know if I could of sat down and done a course”

Another project partner agreed, elaborating that while there was interest in IncludeMe™, due to being overwhelmed, many caregivers are unable to engage with a training like this, they stated:

> “We sent them [recruitment material] out to everybody by email. We talked to our support groups. Described the program and the interest was there. However, … it's very hard for a lot of our caregivers to just even initiate a phone call, let alone getting on to a program right, so that initiation part I think was a bit of a of a hurdle for a lot of them … They're so overwhelmed and so burnt out that that's just one more thing on their plate”

There was also discussion around the fact that new caregivers have limited time between caregiving, caring for themselves, and developing new skills and knowledge. Several partners explained that due to limited time, caregivers will only prioritize activities that are helpful to meeting needs, which might explain the low engagement rate in this evaluation. They stated:

> “this tells me something about the amount of time that caregivers have to devote to anything that's not directly pertinent to the caregiver in the moment. So, I think that's part of the issue with the amount of respondents”

> “At the end of the day, when you're caring for somebody, you sit down. You wanna put your feet up. A lot of them [caregivers] just don't have that mental energy to do one more thing in the day”

Reaching new caregivers to PLWD early in their journey before they are in crisis is difficult due stigma, with many of these caregivers struggling to accept their role and not being open to receiving support (Boots et al., 2017). The representative from the project partner organization Alzheimer Society of Lanark Leeds Grenville said they have been trying without success to connect to this group, stating:

> “it's honestly a mountain that I've been trying to climb for the 14 years I've been with this society. How can I get to people soon enough right for the early state, early diagnosis and all that?” … because this could be a very useful tool for a huge campaign to promote that”

This limited connection to the target audience, and limited understanding about their needs was a barrier to developing and executing the evaluation of IncludeMe™. One of the main challenges that created low engagement seems to be a mismatch between the reality of the target audience and the needs IncludeMe™ addresses. One suggestion from a caregiver expert-by-experience is to target a different audience, the wider circle of caregivers surrounding the primary caregiver and the PLWD who are not in crisis and have time for a learning resource like IncludeMe™. They explained:

> “Caregivers who are on the journey and get no help or no understanding from family members, children, offspring. Offspring live a couple of blocks away that don't come and help their mom. So, it's that population somehow really needs to get involved with this,

> not with an expectation that they're gonna be a caregiver, but so they have an understanding of the world of the person with dementia and the person who is looking after it."

Learning resource design: From the data we know many participants completed less than half of the lessons, which for some was because the content was not new and for some because of difficulties navigating the 'choose your own adventure' design and glitches and frustrations with the user-interface. A representative from the Alzheimer Society of Lanark Leeds Grenville said the feedback they received was that the training was overwhelming regarding where to start, stating, "If caregivers don't know where to start – such as "self care" module, they will simply give up". A participant's comment echo this, stating they want, "a more structured and linear approach to navigating through the modules". A project partner reflected on the miscommunication about the training stating, "I guess people didn't understand that it was intended to be something that you could spend 5 minutes with and then go back to, there was never a statement that you have to sit down and do all of it". Another project partner built on these ideas to suggest an adaptation, stating, "maybe there needs to be a little more pre work in letting folks know how to navigate through the system".

A representative from the project partner organization Addiev Corporate Training provided a recommendation to continue monitoring compatibility between design ideas with the capability of the technology available, recommending:

> "Once we were in the design phase to really look at what we're trying to achieve and the tech we've chosen and kind of revisit and make sure because as we as we adopted the choose your own adventure model for example, that caused some complications in terms of how things were checked off in the LMS [learning management system] because we're using a free system, we're limited by the functionality. So, there were a lot of components that created barriers for the learners"

Overall, challenges with external factors, compatibility between the learning resource characteristics with the target audience, and the design of the learning management system may point to reasons the evaluation had low engagement with the target audience and did not meet minimum sample requirements.

7. Key Takeaways to Support Refinement, Scale, and Spread

From this evaluation and the project partners debrief session there are two important takeaways to guide future adaptations of IncludeMe™:

1. **Improve ease of use:** It will be important for future adaptations of IncludeMe™ to consider how to design the learning management system to improve user experience by implementing the following recommendations: a) allowing for repeat log-ins, b) making

table of contents more prominent, c) upgrading the interface to be less “clunky” with less information, d) making sure progress is accurately tracked through the training, e) providing video clips instead of animations, which were slow and cumbersome, f) making it easier to access resources using simple text documents and adding more resources, and g) offering an audio reader. Attending to these usability challenges may increase the amount of the training people complete and improve the overall impact of IncludeMe™.

2. **Improve compatibility between IncludeMe™ and target audience:** Representatives from the Alzheimer Society of Lanark Leeds Grenville and other project partners shared by the time new caregivers of PLWD are reaching out for services they are often in crisis with little time to complete online learning resources, and desire respite and in-person support. To improve compatibility between IncludeMe™ and the target audience there are two recommendations: 1) use recruitment methods to reach caregivers earlier in their journey before crisis who have a higher need for knowledge of person-centred dementia care. Other learning resources have had some success recruiting from memory clinics (Boots et al., 2017); and 2) purposefully target new caregivers within the broader circle of care. This approach aligns with project partner’s definition of caregiver as a family member, friend, neighbour, or other community member. This second approach would likely also require adaptations to the content of the training so that scenarios are familiar to caregivers beyond the primary caregiver who lives with the PLWD.

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9. Appendices

9.1 Appendix A: Before Training (T1) Survey

We'd like to ask you some questions to know some background information so that we can describe the characteristics of people participating in this study.

1. To understand if the area you live in impacts experience of this training, please indicate the response that best reflects where you live:

- ○ Metropolitan area (more than 150,000 inhabitants)
- ○ Urban area (between 150,000 and 10,000 inhabitants)
- ○ Rural area (less than 10,000 inhabitants)

2. Please tell us **your** relationship to the person showing signs of dementia or who is newly diagnosed with dementia:

- ○ Spouse
- ○ Child
- ○ Sibling
- ○ Grandchild
- ○ Other (relative, in-law, neighbor, friend)

3. To understand if age impacts experience of this training, please indicate your age:

- ○ 24 or younger
- ○ 25 – 34
- ○ 35 – 44
- ○ 45 – 54
- ○ 55 - 64
- ○ 65 or older

4. To understand if gender impacts experience of this training, please indicate how you identify:

- ○ Woman
- ○ Man
- ○ Another gender identity
- ○ I prefer not to answer

5. The Employment Equity Act defines visible minorities as "persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour". Do you identify as a member of a visible minority in Canada?

- ○ Yes
- ○ No
- ○ Prefer not to answer

6. To understand if Indigeneity impacts experience of this training, please indicate if you identify as First Nation, Inuk/Inuit, or Metis:

- ○ Yes
- ○ No
- ○ Prefer not to answer

7. To understand if education impacts the experience of this training, please indicate the highest level of school you have completed

- ○ Less than high school degree
- ○ High school degree or equivalent (e.g., GED)
- ○ Some college or university but no degree
- ○ Associate degree (e.g., college diploma)
- ○ Bachelor degree
- ○ Graduate degree

8. To understand if income impacts experience of this training, please indicate if you ever have difficulty paying your bills at the end of the month

- ○ Yes
- ○ No
- ○ Prefer not to answer

Dementia Attitudes Scale DAS- 6

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym “PLWD” in each question stands for “person living with dementia”

	strongly disagree	disagree	somewhat disagree	neither agree nor disagree	somewhat agree	Agree	Strongly agree
1. It is rewarding to work with PLWD	1	2	3	4	5	6	7
2. I am comfortable touching PLWD	1	2	3	4	5	6	7
3. I feel relaxed around PLWD	1	2	3	4	5	6	7
4. PLWD are creative	1	2	3	4	5	6	7
5. It is possible to enjoy interacting PLWD	1	2	3	4	5	6	7
6. PLWD can enjoy life	1	2	3	4	5	6	7

Questions 1-3 = comfort subscale. Questions 4-6 = person-centred knowledge subscale
(Clark et al., 2022)

The Preparedness for Caregiving Scale

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

The questions relate to the person living with dementia (PLWD) for whom you provide care be it your family member or friend.

	Not at all prepared	Not too well prepared	Somewhat prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family/friend's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of their emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for them?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family/friend?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve them?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family/friend?	0	1	2	3	4

(Stewart & Archbold, 1986, 1994)

Revised Scale for Caregiving Self-Efficacy

We are interested in how confident you are that you can keep up your own activities and respond to caregiving situations. Please think about the questions carefully and be as honest as you can about what you think you can do. Please think about each question and rate your degree of confidence from 0 to 100. For example, a 50% confidence rating would mean that if you gave it your best effort, chances are about 50-50 that you could perform the activity.

Please make all your ratings based on what you could do TODAY as the person you are NOW rather than on the person you used to be or the person you would like to be. Just rate how you think you would do as you are TODAY.

Self-Efficacy for Obtaining Respite **How confident are you that you can do the following activities?**			
How confident are you that you…	Cannot do at all	Moderately can do	Certain can do
1. can ask a friend/family member to stay with PLWD for a day when you need to see the doctor yourself?	0 10 20 30	40 50 60 70	80 90 100
2. ask a friend/family member to stay with PLWD for a day when you have errands to be done?	0 10 20 30	40 50 60 70	80 90 100
3. ask a friend or family member to do errands for you?	0 10 20 30	40 50 60 70	80 90 100
4. ask a friend/family member to stay with PLWD for a day when you feel the need for a break?	0 10 20 30	40 50 60 70	80 90 100
5. ask a friend/family member to stay with PLWD for a week when you need time for yourself?	0 10 20 30	40 50 60 70	80 90 100
Self-Efficacy for Responding to Disruptive Patient Behavior			
How confident are you that you can do these activities?	Cannot do at all	Moderately can do	Certain can do
6. When PLWD forgets your daily routine and asks when lunch is right after you've eaten, how confident are you that you can say things to yourself to calm you down?	0 10 20 30	40 50 60 70	80 90 100
7. When you get angry because PLWD repeats the same question over and over, how confident are you that you can say thing to yourself that calm you down?	0 10 20 30	40 50 60 70	80 90 100
8. When PLWD complains to you about how you're treating him/her, how confident are you that you can respond without arguing	0 10 20 30	40 50 60 70	80 90 100

back? (e.g., reassure or distract him/her?)											
9. When PLWD asks you 4 times in the first one hour after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?	0	10	20	30	40	50	60	70	80	90	100
10. When PLWD interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?	0	10	20	30	40	50	60	70	80	90	100

(Steffen et al, 2002)

9.2 Appendix B: After Training (T2) Survey

How much of the IncludeMe™ - A starting point for Dementia caregivers program did you complete?

- ○ 1-5 lessons
- ○ more than 5 lessons

To understand if access to social resources impacts experience of this training, please indicate if you ever have difficulty connecting with social services to support your needs.

- ○ Yes
- ○ No
- ○ Prefer not to answer

To understand if access to health resources impacts experience of this training, please indicate if you ever have difficulty connecting with health services to support your needs.

- ○ Yes
- ○ No
- ○ Prefer not to answer

Dementia Attitudes Scale DAS- 6

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym "PLWD" in each question stands for "person living with dementia"

	strongly disagree	disagree	somewhat disagree	neither agree nor disagree	somewhat agree	Agree	Strongly agree
1. It is rewarding to work with PLWD	1	2	3	4	5	6	7

2. I am comfortable touching PLWD	1	2	3	4	5	6	7
3. I feel relaxed around PLWD	1	2	3	4	5	6	7
4. PLWD are creative	1	2	3	4	5	6	7
5. It is possible to enjoy interacting PLWD	1	2	3	4	5	6	7
6. PLWD can enjoy life	1	2	3	4	5	6	7

**Questions 1-3 = comfort subscale. Questions 4-6 = person-centred knowledge subscale*
(Clark et al., 2022)

The Preparedness for Caregiving Scale

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.
The questions relate to the person living with dementia (PLWD) for whom you provide care be it your family member or friend.

	Not at all prepared	Not too well prepared	Somewhat prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family/friend's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of their emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for them?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family/friend?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle	0	1	2	3	4

emergencies that involve them?					
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family/friend?	0	1	2	3	4

(Stewart & Archbold, 1986, 1994)

Revised Scale for Caregiving Self-Efficacy

We are interested in how confident you are that you can keep up your own activities and respond to caregiving situations. Please think about the questions carefully and be as honest as you can about what you think you can do. Please think about each question and rate your degree of confidence from 0 to 100. For example, a 50% confidence rating would mean that if you gave it your best effort, chances are about 50-50 that you could perform the activity.

Please make all your ratings based on what you could do TODAY as the person you are NOW rather than on the person you used to be or the person you would like to be. Just rate how you think you would do as you are TODAY.

Self-Efficacy for Obtaining Respite
How confident are you that you can do the following activities?

How confident are you that you…	Cannot do at all				Moderately can do				Certain can do		
1. can ask a friend/family member to say with PLWD for a day when you need to see the doctor yourself?	0	10	20	30	40	50	60	70	80	90	100
2. ask a friend/family member to stay with PLWD for a day when you have errands to be done?	0	10	20	30	40	50	60	70	80	90	100
3. ask a friend or family member to do errands for you?	0	10	20	30	40	50	60	70	80	90	100
4. ask a friend/family member to stay with PLWD for a day when you feel the need for a break?	0	10	20	30	40	50	60	70	80	90	100

5. ask a friend/family member to stay with PLWD for a week when you need time for yourself?	0 10 20 30 40 50 60 70 80 90 100		
Self-Efficacy for Responding to Disruptive Patient Behavior			
How confident are you that you can do these activities?	Cannot do at all	Moderately can do	Certain can do
6. When PLWD forgets your daily routine and asks when lunch is right after you've eaten, how confident are you that you can say things to yourself to calm you down?	0 10 20 30 40 50 60 70 80 90 100		
7. When you get angry because PLWD repeats the same question over and over, how confident are you that you can say thing to yourself that calm you down?	0 10 20 30 40 50 60 70 80 90 100		
8. When PLWD complains to you about how you're treating him/her, how confident are you that you can respond without arguing back? (e.g., reassure or distract him/her?)	0 10 20 30 40 50 60 70 80 90 100		
9. When PLWD asks you 4 times in the first one hour after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?	0 10 20 30 40 50 60 70 80 90 100		
10. When PLWD interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?	0 10 20 30 40 50 60 70 80 90 100		

(Steffen et al, 2002)

Overall, how was your experience using the training program?

- ○ Very poor
- ○ Poor
- ○ Fair
- ○ Good
- ○ Very good

Evaluation of IncludeMe™ - A Starting Point for Dementia Caregivers

Overall, how was your experience exploring and navigating the training program (exploring scenarios, downloading resources, completing activities, etc.)?

- ○ Very difficult
- ○ Difficult
- ○ Neutral
- ○ Easy
- ○ Very easy

Overall, how familiar do the challenges portrayed in the training program feel to you?

- ○ Not familiar at all
- ○ Slightly familiar
- ○ Somewhat familiar
- ○ Moderately familiar
- ○ Extremely familiar

Overall, how likely are you to use the tips, tools, and resources from the training program in your role as a caregiver?

- ○ Very unlikely
- ○ Unlikely
- ○ Not Sure
- ○ Likely
- ○ Extremely Likely

Overall, how useful is the training program to meeting your educational needs as a caregiver?

- ○ Not useful at all
- ○ Slightly useful
- ○ Neutral
- ○ Useful
- ○ Very useful

Do you have any recommendations for improving the program?

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9.3 Appendix C: Psychometric Properties of the Measurement Scales

Preparedness for Caregiving Scale	Caregiver preparedness will be assessed using Archbold et al.'s (1990) Preparedness for Caregiving Scale. This is an 8-item, 5-point Likert scale with response options ranging from not at all prepared (0) to very well prepared (7). A total score ranging from 0 to 32 is calculated by summing the responses for all items, with a higher score indicating more feelings of preparedness. Unidimensionality and satisfactory internal consistency of this scale demonstrated Cronbach's alpha values of ≥0.9 in caregivers of patients with serious illness including dementia (Henriksson et al., 2012).
Revised Scale for Caregiving Self-Efficacy	Caregiver self-efficacy will be assessed using Steffen et al.'s (2002) Revised Scale for Caregiving Self-Efficacy. We will use two of the three subscales resulting in a 10-item scale with two evenly distributed domains (a) obtaining respite, and (b) responding to disruptive patient behaviors. For each item, caregivers are asked to rate their level of confidence (from 0% to 100%) that they could perform the activity if they gave it their best effort. Each subscale is scored, with higher scores indicating higher levels of self-efficacy (Steffen et al., 2002). Tests for the internal reliability of the subscales yielded Cronbach's alpha ranging from .79 to .95 and were found to have strong reliabilities and outcomes to justify self-report administration (Steffen et al., 2019)
Dementia Attitudes Scale - 6	Knowledge of person-centred dementia care and attitudes towards PLWD will be measured using the Dementia Attitudes Scale (Clark et al., 2023). This is a 6-item, 7-point Likert scale (1 =strongly disagree; 7=strongly agree). There are two evenly distributed subscales: person-centered dementia knowledge and social comfort. Items for each subscale are averaged to compute an overall subscale score. Higher scores indicate more positive attitudes. Tests for internal consistency yielded Cronbach's alpha .83 when tested with a range of adults (Clark et al., 2023).