The Behaviours in Dementia Toolkit: A descriptive study on the reach and early impact of a digital health resource library about dementia-related mood and behaviour changes

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Abstract

Background: Dementia is a syndrome with a high global prevalence that includes a number of progressive diseases of the brain affecting various cognitive domains such as memory and thinking, and the performance of daily activities. It manifests as symptoms across a number of domains, which often include significant mood and behaviour changes. Changed moods and behaviours due to dementia may reflect distress, they are highly varied, and may be stressful for both the person living with dementia and their informal and formal carers. To provide dementia care support specific to mood and behaviour changes, the Behaviours in Dementia Toolkit website was developed using human-centered design principles. The Behaviours in Dementia houses a user-friendly, digital library of over 300 free, practical and evidence-informed resources to help all care partners better understand and compassionately respond to behaviours in dementia so they can support people with dementia to live well.

Objective: To determine whether the development and implementation of the Behaviours in Dementia Toolkit was successful in creating website users and to understand the platform’s early impact.

Methods: A multi-method, descriptive study was conducted in the early post-launch period to examine reach, engagement, knowledge change, behaviour change, and website impact outcomes and measures via Google Analytics and an electronic survey of website users.

Results: From February 4 to March 31, 2024 there were 76,890 unique visitors to the Behaviours in Dementia Toolkit from 109 countries. Of 76,890 unique visitors to the Behaviours in Dementia Toolkit during this period, 16,626 were engaged users (21.6%) from 80 countries. The highest number of unique engaged users were from Canada (n=8,124) with an engagement rate of 37.7%. From March 5, 2024 to March 31, 2024, 100 electronic surveys were completed by website users and included in the analysis. Website users indicated that the Toolkit validated or increased their dementia-care knowledge, beliefs, and activities (82.0%) and they reported that the website validated their current care approaches or increased their ability to provide care (78.0%). Further, 77.0% of respondents indicated that they intend to continue using the Toolkit and 81.6% said they would recommend it to others to review and adopt.

Conclusions: The Behaviours in Dementia Toolkit is a promising tool for sharing practical and evidence-informed information resources to support people experiencing dementia related mood and behaviour changes. Early evaluation of the website has demonstrated significant reach and engagement with users in Canadian and internationally. Survey data also demonstrated high ratings of website relevance, feasibility, intention to use, knowledge change, practice support, and its contribution to dementia guidance.

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Conclusions: The Behaviours in Dementia Toolkit is a promising tool for sharing practical and evidence-informed information resources to support people experiencing dementia related mood and behaviour changes. Early evaluation of the website has demonstrated significant reach and engagement with users in Canadian and internationally. Survey data also demonstrated high ratings of website relevance, feasibility, intention to use, knowledge change, practice support, and its contribution to dementia guidance.

Key words: behaviours in dementia; behavioural and psychological symptoms of dementia; responsive behaviours; internet; mHealth; mobile health; digital health; eHealth; library; digital library; health information resources; caregiving; carer; formal caregiver; informal caregiver; care partner

Introduction

Dementia

Dementia is a syndrome that includes a number of progressive diseases of the brain affecting various cognitive domains such as memory and thinking, and the performance of daily activities [1]. Globally, more than 55 million people have dementia [2]. In 2019, this figure is projected to triple by 2050 [2].

Dementia manifests as symptoms across a number of domains [3]. Dementia-related mood and behaviour changes, often called the behavioural and psychological symptoms of dementia or responsive behaviours, affects nearly all people living with dementia at some point(s) during their disease course [4]; however the ways in which these changes are individually expressed varies widely [5]. A longitudinal study determined that 97.0% of dementia patients living in the community experienced at least one behaviour or mood symptom, most commonly depression, apathy, agitation, or changed motor behaviour like fidgeting and repetitive motion [6]. The occurrence of dementia-related mood or behaviour changes are associated with long term care placement for people living with dementia [7].

Changed moods and behaviours due to dementia are highly complex, varied, stressful [4,5], and may reflect distress and unmet needs from the person living with dementia [8]. These changes are associated with deterioration of relationships, increased caregiver burden, institutionalization, and mortality [9]. A research study identified that an increase in caregiver burden was found to increase the frequency and severity of the behaviours [10]. Formal and informal care partners need assistance to cope with dementia-related mood and behaviour changes to help ease the emotional and physical strain of caregiving [11] and reduce the distress experienced by the person living with dementia [10].

Dementia Care

Around the world, most people with dementia live at home. In low and middle income countries, as many any 94.0% of people living with dementia reside at home. Approximately 65.0% of Americans with dementia live at home [12] and 60.0% of people in long term care have dementia [12,13]. This means that many professional and non-professional individuals will be involved in their care, from spouses, family members, and home care staff to care aides, nursing staff, allied health professionals, and physicians. Dementia-friendly environments, regardless of setting, must have supportive features to allow people with dementia to live well [14].

Quality of life is a significant goal of dementia care across settings. This means dementia care should include person-centered interventions that are tailored to individuals and their care partners [3,4]. New clinical practice guidelines were released in 2024 detailing up-to-date knowledge synthesis on best assessment, treatment, and management approaches for the behavioural and psychological symptoms of dementia [15]. Holistic assessment approaches and psychosocial interventions were key practice recommendations [15]. Previous research has demonstrated that psychoeducational and psychosocial interventions for formal and informal care partners promoting understanding of dementia and managing changes in mood and behaviour result in better health outcomes for people living with dementia [10]. In developing these approaches it is important to address known gaps, including informal caregivers' limited knowledge, skills, attitudes and resources, as well as tailoring interventions to various ethnic and cultural backgrounds [10].

Human-Centered Design in Digital Health Interventions

Human-centered design is a creative approach for developing products to solve complex problems [16]. The human-centered design approach considers a multiplicity of users and systems in the design of an innovation [17]. It is increasingly being used in health care to support preventative, personalized and participatory approaches to care,[16] and to improve the implementation of evidence-based interventions [18,19]. It is widely regarded as the best design approach for creating digital health innovations to impact health care [20]. Employing a human-centered design approach in medical devices has also been shown to reduce the need for modifications and updates after they have been made publicly available, supporting cost-effectiveness [21]. It is a particularly salient approach for developing digital health solutions for older adults [21,22] and specifically for developing effective health websites [23].

Health Information Websites

Health information websites are a common source of complex health information [23]. The internet is the most frequently used venue for older adults seeking health information; however, it is simultaneously the least trusted [24]. Online health information should mitigate this mistrust by demonstrating credibility, supporting ease-of-use, and reducing information overload [24]. Health care providers are increasingly required to use information and communication technologies in their work; however, uptake has not been optimal [25]. Due to the ubiquitous use of the internet and the different ways varied information seekers obtain appropriate information and use it in their lives, health information websites are challenging to design for high usability and maximum benefit [23]. Librarians have been identified as uniquely positioned to help both health care providers and health care consumers optimize digital health through technologies and finding and evaluating health information [26].

The Behaviours in Dementia Toolkit

To support the physical, mental, and social wellbeing of people living with dementia, the World Health Organization developed a global action plan on the public health response to dementia for 2017-2025 laying out seven action areas with associated indicators [27]. In response to three of the WHO's action areas (i.e., #2: dementia awareness and friendliness; #4: dementia diagnosis, treatment, care and support; and #5: support for dementia carers) [27], the Canadian Coalition for

Seniors' Mental Health (CCSMH) developed the Behaviours in Dementia Toolkit (Appendix A). The Toolkit is a free website that contains a user-friendly, digital library of over 300 free resources about dementia-related mood and behaviour changes for informal and formal care partners [28]. Developed using a human-centered design approach, the goal of the Behaviours in Dementia Toolkit is to help all care partners better understand and compassionately respond to behaviours in dementia so they can support people with dementia to live well.

The Behaviours in Dementia Toolkit is written in English and consists of six main webpages. The home page welcomes users to the site and directs them to search the library in a variety of ways to meet their needs. The 'What are Behaviours in Dementia?' page provides important background information on dementia as well as mood and behaviour changes and directs users to search the library in different ways than the home page. The 'Search Library' page facilitates key word, advanced, and topic based searching. The 'Recommended Resources' page is the home of narrative blog posts by a variety of experts with experience in dementia. The 'FAQ' page helps people to navigate the Toolkit and provides additional information on the background and project. The 'About Us' page talks about the variety of people engaged in the Toolkit project.

Content throughout the website focuses on increasing awareness of dementia-related mood and behaviour changes and providing hopeful messaging about supporting people with dementia to live well; however, the central function of the website is a digital library of 318 practical and evidence-informed resources. These resources are catalogued and described using a custom, person-centered metadata schema developed specifically for this project to support ease of use between diverse user groups [29]. Resources are categorized and tagged by purpose, intended audience, nature of mood or behaviour change, setting, equity perspective, format, accessibility features, and origin (Appendix B).

Users can search the library catalogue of resources in four different ways: keyword search; advanced search; category search; and, wild card or blank search to look at all of the resources in the collection. Search results can be filtered to expand or narrow options as desired. To obtain more information about a specific resource identified in a search, users click a 'Learn more' button to visit an individual webpage that provides a lay description of the resource content including length and date published. Resources developed by other organizations are not stored within the website; instead users are directed to a hyperlink to access the resource in its original online home. Options are also available on the individual resource page to share it to various social media platforms and to explore related resources on similar topics.

To support informal, non-professional care partners, the resources have been grouped and labeled according to general care needs or purposes. Six categories have been established, including: 1) understand mood or behaviour changes; 2) respond to mood or behaviour changes; 3) learn from people with lived experience; 4) practice self-care; 5) support without medication; and, 6) improve communication. The number of resources in these categories is detailed in Appendix B.

Special attention has also been paid to supporting formal, professional care partners by curating a series of clinical categories. These are: 1) access to clinical guidelines; 2) access to clinical tools and assessments; 3) support with medication and/or deprescribing; and, 4) support without medication. The number of resources in these categories is detailed in Appendix B.

A human centered-design process has three phases: 1) inspiration: build empathy toward users through conversations and experiences to understand barriers experienced and identify facilitators; 2) ideation: generate many solutions to solve the problem informed by inspiration phase; and, 3) implementation: quickly prototype different ideas and solicit feedback [17,28]. In each of these three phases, the Behaviours in Dementia Toolkit project team conducted a number of activities to create a person-centered and user-friendly platform that would attend to diverse audience needs. As part of the inspiration phase of development the Toolkit team sought as much input as possible to formulate the purpose, audiences, scope, content, and even the name of our product. The transition to the ideation phase focused on creativity and developing engaging ways to address our audiences' needs as identified in the inspiration phase. The implementation phase focused on completing development, publicly launching the Behaviours in Dementia Toolkit, and building enthusiasm and awareness so that people would start to use and share the website. These phases were overlapping because of the large volume of activities with differing time requirements and our short project timeline of one year. Table 1 provides a detailed overview of the human-centered design phases and activities that took place in the development process for the Behaviours in Dementia Toolkit.

Table 1. Developing the Behaviours in Dementia Toolkit using human-centered design.

Human-centered design phase	Behaviours in Dementia Toolkit development activity	Activity description
Inspiration (April to October 2023)	Working Group established	Multidisciplinary team met monthly for the duration of the project.
	Survey of information needs and preferences of two primary audiences	Collected 285 surveys from key audiences including health care providers, care partners, etc. identifying their information needs, preferences, and suggestions related to behaviours in dementia.
	Environmental scan to understand how older adults find health information	Conducted an environmental scan to examine the ways older adults find, receive, and share health information. The results of this scan are described in a separate publication [24].
	Environmental scan of existing resources	Conducted an international scan which identified 1408 English-language resources.
	Collection statement and guidelines	Led by a librarian to guide the process of collection development.
	Focus group with older adults/with lived experience	Five older adults with lived experience attended a session to scope and name the Toolkit.
	One-to-one meetings with equity deserving groups	Met with organizations serving the following equity deserving groups including remote & rural; Indigenous; 2SLGBTQIA+; and Black perspectives on dementia care.
	Persona-empathy mapping exercise	Completed six empathy maps of potential user 'personas' to identify knowledge gaps.
	Card sort activity	Seven participants sorted sample resources into

		proposed categories and provided feedback on their suitability as navigation options.
	Let’s Talk Behaviours in Dementia webinar	145 people attended our webinar. In the Q&A and pre/post poll we learned about information needs of health care providers and care partners.
Ideation (August 2023 to January 2024)	Wireframe development	Worked with web design contractor to mock up website and library.
	Custom metadata schema development	Developed a system of categorizing and naming to facilitate the search functions of the library and supply consistent clear language descriptions for each resource. This process is detailed in a separate publication [29].
	Content development	Wrote content for website and library pages, headers/footers, buttons, filters, etc.
	Custom illustrated characters	Worked with illustrator contractor to create characters and illustrations for the Toolkit.
	Indigenous Welcome to the website	Worked with Elder Larry Frost to develop an Indigenous Welcome for the homepage.
	Selection & curation of resources	Led by a librarian. Selected 318 relevant, practical, evidence-informed, and inclusive resources to include in the Toolkit.
	Narrative blog posts co-created with experts	Worked with 13 experts to co-develop experiential articles containing resource recommendations.
	Informational videos developed	Created three informational videos to support website use and navigation.
	Specialized infographics for different audiences developed	Developed 18 infographics curating resources for different audiences, settings, and types of dementia.
Implementation (November 2023 to March 2024)	Beta website development	Worked with web design contractor to develop a beta version of the website and library.
	User satisfaction of beta site examined	Analyzed 12 individual interviews. This sub-study will be detailed in a separate publication [30].
	Usability of beta site examined	Analyzed 12 individual interviews. This sub-study will be detailed in a separate publication currently in development.
	Acceptability of content on beta site assessed	Analyzed 76 surveys. This sub-study will be detailed in a separate publication currently in development.
	Metadata schema refined	Consulted with advocates, researchers, and people with lived experience to find a balance of accurate, clear, and inclusive terminology. This process is detailed in a separate publication [29].
	Custom lay descriptions and	Led by a Library Technician and Librarian.

	descriptive metadata records developed for each resource using metadata schema	
	Website re-development	Worked with web design contractor to make changes based on usability study. Both functional and design changes were made. This sub-study will be detailed in a separate publication currently in development.
	Outreach activities	Many strategies used to promote the Toolkit.
	Reach of website post-launch assessed	See Methods and Results.
	Impact of website post-launch assessed	See Methods and Results.

The Behaviours in Dementia Toolkit was made public in February 2024. Promotion of the website was comprehensive and extensive from January 2024 through March 2024. Outreach activities targeted to audiences in Canada included direct emails and presentations; a press release and media engagement; sponsored articles in digital and print magazines; and, distribution of 26,000 postcards publicizing the Toolkit. International outreach activities included social media posts and Google, Facebook, and YouTube advertisements. Collectively these efforts connected us with a potential audience of approximately seven million people.

Methods

To determine whether the development and implementation of the Behaviours in Dementia Toolkit was successful, we conducted a multi-method, descriptive study in the early post-launch period (i.e., up to two months post-launch). The study was designed to address the following research questions:

- How many users visited the Behaviours in Dementia Toolkit?
- How did users engage with the Behaviours in Dementia Toolkit?
- How did users rate their change in knowledge about behaviours in dementia and effective responses after using the Behaviours in Dementia Toolkit?
- How did users anticipate their care may change after using the Behaviours in Dementia Toolkit?
- How did users rate the contribution of the Behaviours in Dementia Toolkit to dementia guidance in Canada?

These research questions were mapped to five main outcomes and nineteen outcome measures (Table 2). Our study received research ethics board approval from Baycrest (REB# 24-07).

Table 2. Study questions, outcomes, and measures.

Research question	Outcome	Outcome measure	Data collection tool
How many users	Reach	• number of unique visitors	Google Analytics

visited the website?		• number of unique visitors by region • number of unique visits • number of return visits • bounce rate (definition below)	
How did users engage with the website?	Engagement	• engaged users (definition below) • engaged sessions (definition below) • average session duration • average pages viewed per session • engagement rate per webpage (definition below) • top keyword search terms used • top resources accessed	Google Analytics
How did users rate their change in knowledge about behaviours in dementia and effective responses?	Knowledge change	• change in knowledge after using Toolkit	Electronic survey
How did users anticipate their care may change?	Behaviour change	• change in ability to provide care to people experiencing behaviours in dementia after using Toolkit	Electronic survey
How did users rate the website's contribution to dementia guidance in Canada?	Website impact	• relevance of Toolkit • feasibility of Toolkit • intention to continue to use Toolkit • Toolkit makes a meaningful contribution to improving access and use of dementia guidance and support in Canada • would recommend the Toolkit to others to use	Electronic survey

Google Analytics

Reach and engagement outcome measures were collected via Google Analytics [30]. Google Analytics 4 defines engagement metrics as follows: 1) engaged users have completed a session lasting longer than 10 seconds, having a key event, or having at least two page or screen views; 2) engaged sessions last longer than 10 seconds, have a key event, or have at least two page views or screen views; 3) bounce rate is the percentage of sessions that were not engaged; and, 4) engagement rate measures the percentage of visitors who interacted with content or spent a significant amount of time on a specific page [31].

Data were collected from February 4, 2024 to March 31, 2024. Google Analytics cookies collect information including IP address, device type and operating system, referring URLs, geolocation, and pages visited. This information is de-personalized and not connected to any individual. Website users were advised of our use of Google Analytics with our website privacy policy and provided tools and instructions to opt out [32].

Electronic Survey

Knowledge change, behaviour change, and website impact measures were collected through an electronic survey of website users via Qualtrics (Appendix C) [33]. The survey and survey recruitment were in English-only. Survey recruitment took place from March 5 to March 31, 2024. Website users were invited to participate in the survey through: 1) a banner with an invitation and survey link in the website header; 2) two Facebook advertisements; 3) the CCSMH e-newsletter and social media posts; and, 4) direct emails from members of the Behaviours in Dementia Working Group to their networks. Potential participants were first presented with a digital information letter about the study at the survey link. Advancing to the survey implied their consent to participate. Once the data collection period ended, the survey was closed for data collection and the Excel file was downloaded from Qualtrics to CCSMH's secure server for cleaning, analysis, and secure, long-term storage. Survey responses were included in analysis if all demographic items and at least one outcome measure were completed.

Data Analysis

Quantitative data from Google Analytics and the electronic survey were analyzed descriptively using Google Analytics 4 [34] and Microsoft Excel [35].

Results

Google Analytics

From February 4 to March 31, 2024 there were 76,890 unique visitors to the Behaviours in Dementia Toolkit from 109 countries. The highest number of unique visitors were from the Philippines (n=31,816); Canada (n=21,530); Nigeria (n=8,086); Malaysia (n=3,962); and, Uganda (n=2,319). Within Canada, where the Toolkit was developed, unique visitors opened the Toolkit website from all provinces and territories: Ontario (n=8,871); Quebec (n=4,958); British Columbia (n=2,788); Alberta (n=1,925); Nova Scotia (n=887); Manitoba (n=831); New Brunswick (n=649); Saskatchewan (n=526); Newfoundland and Labrador (n=273); Prince Edward Island (n=121); Northwest Territories (n=14); Yukon (n=11); and, Nunavut (n=6).

Of 76,890 unique visitors to the Behaviours in Dementia Toolkit during this period, 16,626 were engaged users (21.6%) from 80 countries. The highest number of unique engaged users were from Canada (n=8,124) with an engagement rate of 37.7%. Unique engaged users in Canada visited the Toolkit from all provinces and territories: Ontario (n=3,637); British Columbia (n=1,546); Quebec (n=1,091); Alberta (n=842); Nova Scotia (n=420); Manitoba (n=328); New Brunswick (n=271); Saskatchewan (n=162); Newfoundland and Labrador (n=95); Prince Edward Island (n=51); Northwest Territories (n=5); Yukon (n=5); and, Nunavut (n=1).

Reach and engagement outcome measures and results are described in Table 3. The results are reported for two groups: total visitors who came to the website and the sub-group of visitors with engaged sessions on the website.

Table 3. Reach and engagement outcome measures and results.

Outcome measures	Results
Total visitors	
Total number of unique visitors	n=76,890
Number of unique views	n=98,094
Bounce rate	70.9%
Number of return views	n=21,204
Mean session duration	1m 49s
Mean pages per session	n=1.64
Engagement rate for homepage	28.9%
Engagement rate for behaviours in dementia information page	84.2%
Engagement rate for search library page	93.7%
Engagement rate for advanced search page	91.3%
Engagement rate for recommended resources page	90.0%
Engagement rate for about page	86.9%
Engaged users	
Number of unique engaged users	n=16,626
Number of unique views	n=23,714
Number of return views	n=7,088
Mean session duration	3m 26s
Mean pages per session	n=2.65
Engagement rate of users in Philippines	15.0%
Engagement rate of users in Canada	37.7%
Engagement rate of users in Nigeria	14.5%
Engagement rate of users in Malaysia	16.5%
Engagement rate of users in Uganda	16.9%

The most often used keyword terms used to search the library catalogue were: 1) driving (n=22); 2) won’t eat (n=6); and 3) apathy (n=5). Of the 318 resources in the collection, the five most frequently viewed were: 1) caregiver tip sheet: anger, frustration, and fidgeting (n=604); 2) supporting independence and personhood (n=367); 3) five seriously fun ideas from a recreation therapist (n=278); 4) effective online supports help navigate behaviours in dementia (n=245); and, 5) ten helpful resources to increase meaningful engagement (n=169).

Electronic Survey

From March 5, 2024 to March 31, 2024, 297 people accessed the survey information page; 230

people consented to participate (77.4% consent rate); 104 started the survey (45.2% response rate); and, 100 surveys were included in the analysis (96.2% completion rate).

All survey respondents resided in Canada in the following regions: Ontario (n=49, 49.0%); British Columbia (n=18, 18.0%); Alberta (n=11, 11.0%); Nova Scotia (n=6, 6.0%); Manitoba (n=6, 6.0%); Saskatchewan (n=5, 5.0%); New Brunswick (n=2, 2.0%); Newfoundland and Labrador (n=1, 1.0%); Northwest Territories (n=1, 1.0%); and, Prince Edward Island (n=1, 1.0%). There were no respondents from Nunavut, Quebec, or Yukon.

Survey respondents identified as (multi-response): caring for someone living with dementia (n=40, 40.0%); having a general interest in dementia (n=33, 33.0%); knowing someone living with dementia (n=27, 27.0%); working in a clinical or non-clinical role connected to dementia (n=17, 17.0%); other role (n=17, 17.0%); or, someone living with dementia (n=3, 3.0%).

Knowledge change, behaviour change, and website impact results are reported in Table 4.

Table 4. Knowledge change, behaviour change, and website impact outcome measures results.

Outcome	Survey question (number and percentage of respondents completing the question)	Response (number, percentage of respondents)
Change in knowledge	How did the Behaviours in Dementia Toolkit impact your knowledge about behaviours in dementia? *(n=100; 100.0%)*	• I had no change in knowledge (n=18, 18.0%) • The Toolkit validated my current knowledge, beliefs, and activities (n=40, 40.0%) • The Toolkit increased my knowledge of the topic (n=42, 42.0%)
Change in behaviour	How did the Behaviours in Dementia Toolkit impact your ability to provide care to people experiencing behaviours in dementia? *(n=97; 97.0%)*	• I had no change in my ability to provide care (n=21, 21.6%) • Toolkit validated my current approaches to care (n=43, 44.3%) • The Toolkit increased my ability to provide care (n=33, 34.0%)
Website impact	The Behaviours in Dementia Toolkit is relevant to your situation. *(n=84; 84.0%)*	• Strongly Disagree (n=2, 2.4%) • Somewhat Disagree (n=3, 3.6%) • Neither Agree or Disagree (n=15, 17.9%) • Somewhat Agree (n=30, 35.7%) • Strongly Agree (n=34, 40.5%)
	The Behaviours in Dementia Toolkit is feasible to use in your situation. *(n=83; 83.0%)*	• Strongly Disagree (n=2, 2.4%) • Somewhat Disagree (n=4, 4.8%) • Neither Agree or Disagree (n=15, 18.1%) • Somewhat Agree (n=27, 32.5%) • Strongly Agree (n=35, 42.1%)
	The Behaviours in Dementia Toolkit is something you intend to use. *(n=86; 86.0%)*	• Strongly Disagree (n=3, 3.5%) • Somewhat Disagree (n=3, 3.5%) • Neither Agree or Disagree (n=13, 15.1%)

		• Somewhat Agree (n=30, 34.9%) • Strongly Agree (n=37, 43.0%)
	The Behaviours in Dementia Toolkit makes a meaningful contribution to improving access and use of dementia guidance in Canada. *(n=83; 83.0%)*	• Strongly Disagree (n=3, 3.6%) • Somewhat Disagree (n=2, 2.4%) • Neither Agree or Disagree (n=12, 14.5%) • Somewhat Agree (n=21, 25.3%) • Strongly Agree (n=45, 54.2%)
	I would recommend the Behaviours in Dementia Toolkit to others to use. *(n=83; 83.0%)*	• Strongly Disagree (n=2, 2.4%) • Somewhat Disagree (n=3, 3.6%) • Neither Agree or Disagree (n=7, 8.4%) • Somewhat Agree (n=22, 26.5%) • Strongly Agree (n=49, 59.0%)

Discussion

Principal Results

Reach and engagement

The Google Analytics results showed high traffic from users in the Philippines, Canada, Nigeria, Malaysia, and Uganda. This is likely a result of our Google, Facebook and YouTube advertisements targeted English-speaking countries around the world, which are optimized towards low-middle income countries where the cost per click is lower (e.g., cost for users in Philippines is $0.02 per click and cost for users in the United States is $1.21 per click). It may also reflect less access to health information and care in Sub-Saharan Africa and Southern Asia [36]. The second largest group and most engaged users were from Canada. This was expected as the project took place in Canada and we incorporated extensive outreach activities across Canada.

The website did experience a high bounce rate of 70.9% compared to the average bounce rate for health care websites of 58.3% [37]. Users tend to form an opinion about a website in 0.05 seconds [38], so it is likely that our paid advertisements through Google and Facebook were not optimally targeted to our intended audiences, which is likely why they did not remain on the website beyond ten seconds or engage with web content. We would expect the bounce rate to improve as our more targeted and sustained outreach activities (e.g., postcard distribution; direct emails and meetings; library listings, etc.) grow our engaged user base and the Behaviours in Dementia Toolkit becomes more deeply embedded in the dementia care information ecosystem. This data point should be examined at regular intervals over time to ensure our strategies are working as intended to attract users who find the website useful to support their caregiving.

Examining the sub-set of engaged users, our results demonstrate a high number of both users and sessions for the Behaviours in Dementia Toolkit. During the study period 16,626 engaged users visited the website; a figure nearly seven times higher than the number of average users for health care websites [37]. Additionally, those users had 23,714 sessions on the website which is nearly six times higher than the average number of sessions for health care websites [37]. This is likely a result of the novelty of the website and points to the Behaviours in Dementia Toolkit meeting a real and present need for informal and formal care partners of people experiencing mood issues and behaviours in dementia. The usefulness of the website is bolstered by high engagement rates on the additional main navigation (i.e., level 1) pages in the Behaviours in Dementia Toolkit (i.e., other than the home page). For comparison, the all industry average engagement rate for level 1 pages is 75.0% and the average engagement rate of level 1 pages for non-profit organizations is 53.0%.[40] Level 1 page engagement rates ranging from 84.2% to 93.7% confirms that the Behaviours in Dementia Toolkit is relevant and engaging; readable and scannable; and facilitates a positive user experience [39].

The return views for both the overall group (21,204, 27.6%) and sub-group of engaged users (7,088; 42.6%) demonstrates that the Behaviours in Dementia Toolkit met its value proposition for providing practical and evidence-informed resources to support people experiencing behaviours in dementia. Users returned, even in the short study timeline, which means they found something of value on the website or in the library. This data point should also be tracked over time to ensure the Behaviours in Dementia Toolkit remains relevant to our key audiences.

Knowledge change, behaviour change, and website impact

The results of the electronic survey further highlighted that the Behaviours in Dementia Toolkit is helping carers of people living with dementia. More than 80.0% of website users indicated that the Toolkit validated (40.0%) or increased (42.0%) their dementia-care knowledge, beliefs, and activities and more than 75.0% of website users indicated that the Toolkit validated their current care approaches (44.3%) or increased their ability to provide care (34.0%). Further, over three quarters of respondents (77.9%) indicated that they intend to continue to use the Toolkit and over four fifths (85.5%) said they would recommend it to others to use. Additional high ratings on relevance (76.2%), feasibility (74.6%), improved access to dementia guidance (79.5%) demonstrate that the Behaviours in Dementia Toolkit will be a highly accessed tool into the future. Particularly as the Behaviours in Dementia Toolkit becomes more widely known, the use of the website becomes integrated into practice, and users return for more and different resources to meet their needs.

Limitations

The Behaviours in Dementia Toolkit is currently an English language website, though it does contain multilingual resources, which limits its generalizability. The evaluation data presented is a snapshot immediately post-launch when we had considerable capacity for outreach. Ongoing monitoring of reach and engagement metrics will confirm whether the Behaviours in Dementia Toolkit remains relevant to users over time. Expansion of the Toolkit to other languages would also facilitate greater uptake in Canada, with over 200 other languages represented in the population [40], and worldwide.

For the electronic survey, fewer participants filled out the survey after consenting (45.2%). This attrition can be attributed to the request for participants to visit the Behaviours in Dementia Toolkit before initiating the survey if they had not yet done so and providing an external link. While the drop in participation was not ideal, it was important that users provide an honest assessment of their website experience, which required them to have used the Behaviours in Dementia Toolkit. Of those that returned or continued with the survey past that request, we observed an excellent survey completion rate (96.2%). To understand the sustained impact of the website, it will be important to conduct a similar survey one year post launch. Soliciting feedback from a higher proportion of formal care partners, from participants proportionally from all provinces and territories, and from non-English speaking users would be helpful to understand the needs and contextual nuances of different roles and locations. The addition of qualitative data collection (e.g., survey questions, focus groups, or interviews) may also be important to solicit users' positive and negative feedback in a more open-ended and detailed fashion.

Comparison with Prior Work

Previous research has demonstrated the critical importance of thoughtful design for digital interfaces to support ease of use, particularly for older adults, including consistent interface and terminology and clear processes [20,41], leading to a user-friendly experience [42,43]. Employing a human-centered design approach in the development of the Behaviours in Dementia Toolkit, we incorporated co-design opportunities to identify problems and solutions at the outset [29], which lead to high reach and engagement as well as positive knowledge change, behaviour change, and website impact results. A 2020 systematic review indicated that co-designed technologies positively impacted disease knowledge, access to health care, patient satisfaction, health outcomes, medical errors, and medical costs [44]. The early stages of these benefits (i.e., change in knowledge and behaviour) are reflected in the results of this study.

Conclusions

The Behaviours in Dementia Toolkit is a promising tool for sharing practical and evidence-informed resources to support people experiencing dementia related mood and behaviour changes. Early evaluation of the website has demonstrated significant reach and engagement with users in Canadian and other countries. Survey data also demonstrated high ratings of website relevance, feasibility, intention to use, knowledge change, practice support, and assessment of its contribution to dementia guidance. Longer term evaluation is needed to monitor these metrics over time to ensure sustained enthusiasm for and usefulness of the website. Future investments in the website could also help expand its offerings to reflect emerging evidence and the unique contexts of a variety of equity deserving groups. Sustained outreach and engagement activities will facilitate the integration of this useful tool in dementia care information ecosystems.

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Conflicts of Interest

None declared.

Abbreviations

2SLGBTQIA+: two-spirit, lesbian, gay, bisexual, transgender, queer, intersex, asexual, and others on the sexual and gender minority spectrum
CCSMH: Canadian Coalition for Seniors' Mental Health
Toolkit: Behaviours in Dementia Toolkit

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Supplementary Files

Multimedia Appendixes

Website screenshots.
URL: http://asset.jmir.pub/assets/e70b1a3720bce140eb9da8e373c37a73.docx

Collection snapshot.
URL: http://asset.jmir.pub/assets/719ce582a940ceb8825b54ba1153881d.docx

Screenshots of evaluation survey in Qualtrics.
URL: http://asset.jmir.pub/assets/0b2b723e5fe1ed84bccfd56dd56c87d6.docx