

Content and Quality of Information Provided on Canadian Dementia Websites



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ABSTRACT

Purpose

Information about dementia is important for persons with dementia (PWD) and their caregivers and the Internet has become the key source of health information. We reviewed the content and quality of information provided on Canadian websites for Alzheimer's disease (AD).

Methods

We used the terms "dementia" and "Alzheimer" in Google to identify Canadian dementia websites. The contents of websites were compared to 16 guideline recommendations provided in Canadian Consensus Conference on Diagnosis and Treatment of Dementia. The quality of information provided on websites was evaluated using the DISCERN instrument. The content and quality of information provided on selected websites were then described.

Results

Seven websites were identified, three of which provided relatively comprehensive and high-quality information on dementia. Websites frequently provided information about diagnosis of dementia, its natural course, and types of dementia, while other topics were less commonly addressed. The quality of information provided on the websites varied, and many websites had several areas where the quality of information provided was relatively low according to the DISCERN instrument.

Conclusions

There is variation in the content and quality of dementia websites, although some websites provide high-quality and relatively comprehensive information which would serve as a useful resource for PWD, caregivers, and healthcare providers. Improvements in the content and quality of information provided on AD websites would provide PWD and their caregivers with access to better information.

Key words: dementia, Alzheimer's disease, Internet, health information

INTRODUCTION

Adults aged 65 and older are the fastest growing age group in Canada and other developed countries. In 2010, 14.1% of the Canadian population was 65 years and older; that figure is projected to increase to 25.5% over the next 50 years.⁽¹⁾ The prevalence of Alzheimer's disease (AD) and related forms of dementia is rapidly increasing with this aging of the population. Currently, there are 500,000 people living with dementia in Canada, which is expected to increase to 1.1 million in the next 30 years.⁽¹⁾ Worldwide, the prevalence of dementia is expected to double in the next 20 years.⁽²⁾

Information needs have been identified and documented in the literature as an important area of concern for persons with dementia (PWD) and their caregivers.⁽³⁻¹⁰⁾ Although physicians and nurses are regarded as the most useful source of information for health-care advice,^(11,12) patients frequently use the Internet when seeking out information about health conditions.^(11,13-16) Patients feel that physicians should encourage use of the Internet to provide information,⁽¹⁷⁾ although physicians may be relatively unprepared to incorporate information from the Internet into medical practice.⁽¹⁸⁾ A survey of primary care physicians and specialists affiliated with dementia centres found that two-thirds of physicians surveyed used Internet-based resources for dementia in their clinical practices at least once per week, and 75% agreed that Internet-based resources are helpful in clinical care.^(13,15) Although physicians also frequently used the Internet for information, they often have concerns regarding variation in the quality of information that is provided on dementia.⁽¹³⁾ Other health-care professionals such as nurses also frequently utilize the Internet as a resource for information,⁽¹⁹⁻²²⁾ although less is known of nurses' use of the Internet for information specific to dementia. Potential limitations of information provided on the Internet include a limited range of information provided on health-related websites, variation in the quality of information, and difficulties for persons to access and comprehend information.^(23,24)

To date there have been relatively few studies examining the content and quality of websites providing information for PWD and their caregivers.^(25,26) To facilitate the use of Internet-based resources for PWD and their caregivers, an understanding of the Internet resources that provide both high-quality and comprehensive information on dementia in Canada is required. Access to information about credible dementia websites will also provide physicians, nurses, allied health professionals, and community service providers with readily available information and resources to support PWD and their caregivers. Therefore, we identified Canadian websites providing information on dementia, and evaluated the content and quality of information provided on these websites.

METHODS

Selection of Websites

Websites were identified by entering the terms “dementia” or “Alzheimer” into www.google.ca between May and June, 2011. These websites were subsequently reviewed in March, 2012 for any major updates. We also assessed the impact of several misspelled versions of both search terms (e.g., dimentia, Alzheimer’s) which had no impact on the search results. During this time period Google was the most commonly utilized Internet search engine in Canada, accounting for 69% of all Internet searches.⁽²⁷⁾ Using the Google advanced search function, we restricted the search to websites originating from Canada. Google searches for dementia websites were performed independently by two authors (WD and DS). The first 10 search engine results pages (100 search results) from Google were reviewed for potentially relevant websites, as Internet users frequently do not review search results beyond the first page of search engine results.⁽²⁸⁾ Each author then generated a list of potential relevant websites from the review of search engine results, and a final list of websites to be reviewed in detail were arrived at by consensus. We only selected websites that provided information that was written for PWD or their caregivers and excluded websites that only provided information for health-care professionals or researchers. The page ranking of each of the selected websites was recorded separately for each of the searches using the terms “dementia” and “Alzheimer”. After selecting the websites for review, the websites were downloaded using the ScrapBook application for the Firefox Internet browser (available at: <https://addons.mozilla.org/en-US/firefox/addon/scrapbook/>) on the same date. This was completed in order to save and annotate the websites in an offline format to account for any potential updates to websites that might have occurred during the review process. For websites that provided information in both English and French, only the English content of the website was reviewed. Several provincial Alzheimer Society websites have been developed in

addition to the national website. However, these provincial websites were excluded from our review because the majority of information about dementia provided on these websites consisted of links to the national Alzheimer Society website. As such, we only evaluated the content and quality of the national website. One website, www.dementiajourney.ca, was an independent website at the time of our initial review but has since been included in the Alzheimer Society of British Columbia website. As this website contained additional information and resources about dementia not available on the national Alzheimer Society website, it was evaluated as a separate website. The remaining websites identified in the search were independent websites providing original content.

Assessment of the Content of Dementia Websites

To determine the content of selected websites, we identified a number of key topics pertaining to the diagnosis and management of dementia as identified in the Canadian Consensus Conference on the Diagnosis and Treatment of Dementia. At the time of our search, the most recent version of these were those published in 2007 and contain recommendations for the evaluation and treatment of AD and related forms of dementia ranging from dementia prevention to management of severe dementia.⁽²⁹⁻³⁶⁾ We focused on those guideline recommendations that were most relevant to individuals with mild-to-moderate dementia and their caregivers based on information from previous studies of the information needs of these groups.^(8-10,37-40) These topics included: providing information on symptoms; evaluation and diagnosis of dementia; prognosis associated with dementia; treatment options; and support for persons with dementia and their caregivers.⁽⁴¹⁾ A total of 16 guideline recommendations were selected to be included in the assessment of website content (Table 1). Two authors searched each included website to determine if the website provided adequate information on each topic related to these guideline recommendations. Each author independently rated the content areas as “Yes” if the topic was addressed or “No” if the topic was not addressed on the website.

Assessment of the Quality of Information on Dementia Websites

A number of instruments have been developed to assess the quality of health information provided on dementia websites.⁽⁴²⁾ To assess the quality of information provided on dementia websites we used the DISCERN instrument. The DISCERN instrument is a standardized rating system developed at the University of Oxford to judge the quality of written consumer health information on treatment choices.⁽⁴³⁾ This method was selected because it pertains specifically to written health information and has been used in other studies examining health information provided on websites.

(44-48) The DISCERN scale is also strongly correlated with other measures of website quality⁽⁴⁸⁾ and evidence-based quality assessments of website information.⁽⁴⁹⁾ The DISCERN instrument can also be used by consumers to rate the quality of online information.^(17,49)

The DISCERN instrument was developed to address the quality of written material with respect to treatment choices. In addition to questions concerning treatment options, the DISCERN criteria also assess quality of life, aims of the material, and whether those aims are achieved. Sample questions

TABLE 1.

Guideline recommendations from the Canadian Consensus Conference on Diagnosis and Treatment of Dementia evaluated on Canadian dementia websites

- | | |
|-----|--|
| 1. | Explanation of difference between normal aging, mild cognitive impairment, and dementia ⁽²⁹⁾ |
| 2. | Cognitive symptoms and other features associated with dementia ⁽³⁰⁾ |
| 3. | Explanation of the different types of dementia including Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia ^(30,31) |
| 4. | Role of cognitive screening tests and neuropsychological evaluation in diagnosis of dementia ⁽³²⁾ |
| 5. | Role of neuroimaging in the evaluation and diagnosis of dementia ⁽³³⁾ |
| 6. | Disclosure of diagnosis to the person with dementia ⁽³⁴⁾ |
| 7. | Evidence for non-pharmacological interventions to treat cognitive symptoms of dementia ⁽³⁵⁾ |
| 8. | Prognosis and natural progression of dementia ⁽³⁵⁾ |
| 9. | Use of cholinesterase inhibitors including risks, benefits associated with treatment ⁽³⁵⁾ |
| 10. | Use of memantine including risks and benefits associated with treatment ⁽³⁵⁾ |
| 11. | Description of behavioral symptoms associated with dementia including depressive symptoms, agitation, psychosis ⁽³⁵⁾ |
| 12. | Community resources that may be helpful to persons with dementia or their caregivers with specific mention Alzheimer Society ⁽³⁵⁾ |
| 13. | Effects of dementia on driving safety ⁽³⁵⁾ |
| 14. | Support networks available to caregivers of individuals with dementia ⁽³⁵⁾ |
| 15. | Identifying caregiver stress and methods to reduce caregiver stress ⁽³⁵⁾ |
| 16. | Information about the genetics of Alzheimer's disease and familial risk of dementia ⁽³⁶⁾ |

include: "Are the aims clear?"; "Is it relevant?"; "Does it refer to areas of uncertainty?"; and "Does it describe the risks of each treatment?". A summary of the DISCERN instrument criteria is provided in Table 2. For each of the 16 criteria, each of the two raters assigned a score for each website ranging from 1 to 5 using the DISCERN handbook (1 = No, 2-4 = Partially addressed, 5 = Yes).⁽⁵⁰⁾ The inter-rater reliability of the DISCERN instrument for rating overall quality of websites has been demonstrated in previous studies^(44,46,48) along with its internal consistency.⁽⁴⁸⁾

Synthesis of Website Content and Quality and Analysis

We summarized the content of each website in tables and calculated the total number of the 16 potential dementia guideline topic areas that were addressed by each website. We also summarized the number of websites that provided

TABLE 2.

DISCERN instrument for judging the quality of written consumer health information on treatment choices⁽⁴³⁾

- | | |
|-----|---|
| 1. | Are the aims clear? |
| 2. | Does it achieve its aims? |
| 3. | Is it relevant? |
| 4. | Is it clear what sources of information were used to compile the publication? |
| 5. | Is it clear when the information used or reported in the publication was produced? |
| 6. | Is it balanced and unbiased? |
| 7. | Does it provide details of additional sources of support and information? |
| 8. | Does it refer to areas of uncertainty? |
| 9. | Does it describe how each treatment works? |
| 10. | Does it describe the benefits of each treatment? |
| 11. | Does it describe the risks of each treatment? |
| 12. | Does it describe what would happen if no treatment is used? |
| 13. | Does it describe how the treatment choices affect overall quality of life? |
| 14. | Is it clear that there may be more than one possible treatment choice? |
| 15. | Does it provide support for shared decision making? |
| 16. | Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices. |

Note: Each item is rated from 1 to 5, with 1 = No, 2-4 = Partially achieved, 5 = Yes.

information on each of the 16 individual guideline topics to identify content areas that were most commonly addressed by the selected websites. A dementia guideline topic received a final rating of “Yes” if at least one of the authors assessed the website as providing adequate information on the guideline topic. The inter-rater reliability of each guideline recommendation rating was assessed using kappa statistics.

We described the quality of information provided in each website in two ways. First we determined whether the website displayed Health on the Net (HON) certification.⁽⁵¹⁾ We then rated each website using the DISCERN criteria. The sum of the scores for all of the DISCERN items was determined for each website (range = 16–80). The DISCERN scores for the two raters were highly correlated ($r = 0.78$, $p = .04$); therefore, we reported the average total DISCERN score for each website. The DISCERN handbook does not specify particular cutoffs for DISCERN item scores to reflect high versus low quality. For the purposes of our study, we selected a score of 3 (Partially addressed) or higher on the DISCERN item to reflect that a website provided information of adequate quality on that item. The overall quality of each website was also evaluated by determining the total number of DISCERN criteria which received an average rating of 3 or higher. The number of websites that had an average score of 3 or higher on each of the individual DISCERN criteria across websites was then reported to highlight common features of higher or lower quality information across all the selected websites. Inter-rater reliability for each DISCERN instrument criteria was assessed by means of weighted kappa statistic. The following thresholds for kappa statistics were used to rate the reliability of the assessments of website content and quality: low inter-rater reliability (0.0–0.39), moderate reliability (0.4–0.7), and high reliability (> 0.7).

RESULTS

Selection of Websites

Using the Google search engine with a restriction to Canadian websites, the term “dementia” identified 1.6 million potential websites, and the term “Alzheimer” identified approximately 998,000 potential websites. Of these, we identified a total of seven Canadian websites which provided information about AD or related forms of dementia that were relevant for PWD and their caregivers (Table 3). These websites varied widely in the amount of content provided, with some websites containing a single webpage (e.g., Veteran Affairs Canada: Dementia and Alzheimer’s Disease), while other websites provided a much larger range of information and resources (Dementia Guide and Dementia Journey). Three websites provided information in both English and French, with the remaining websites only providing English content. The terms dementia and Alzheimer resulted in different relative ranking of the identified websites and there was no clear pattern between search engine ranking and the quality or content of websites.

Content of Canadian Dementia Websites

The average number of dementia guideline content areas addressed across all websites was 7.4 out of a total of 16 content areas (49.1%) (Table 4). The total number of content areas ranged from 5 of 16 areas (31%; Veteran Affairs Canada) to 16 of 16 areas (100%; Dementia Guide). There was variation across all the evaluated websites on the topics about which websites provided information. Information on the diagnosis of dementia and symptoms associated with dementia were the most commonly addressed topics, with all websites providing information on these areas. Other topics were addressed less frequently, such as the difference between mild cognitive impairment and dementia, disclosure of a diagnosis of dementia, use of cholinesterase inhibitors, and the effectiveness of non-pharmacological treatment, which were only addressed by 4/7 websites (57%), respectively. The average kappa value for each of the rating of the dementia content areas was 0.53, indicating moderate inter-rater reliability.

Quality of Information Provided on Canadian Dementia Websites

Two websites had HON certification (www.alzheimer.ca, www.dementiaguide.com). The average value all the DISCERN instrument items within each website ranged from 1.47 to 4.16, indicating variation in the quality of information provided on each site (Table 5). The average of the sum of the DISCERN scores was 48.4 (SD = 17.8) and varied from 23.5 (SD = 2.1) to 66.5 (0.7). Most websites provided explicit aims for the website (6/7, 86%), were rated as being reliable and unbiased (6/7, 86%), and provided sources of additional information (6/7, 86%). However, other aspects of quality of information were less commonly addressed, such as a discussion on the course of illness without treatment (0/7, 0%) or the impact of treatment on quality of life (1/7, 14%). The kappa value for the overall rating of website quality was 0.48, indicating moderate degree of inter-rater reliability. Overall, three websites provided both high-quality and relatively comprehensive information on dementia (www.alzheimer.ca, www.dementiaguide.com, and www.dementiajourney.ca).

DISCUSSION

We identified seven Canadian websites providing information on dementia that caregivers and persons with dementia might use to for information on AD. Three of these websites were relatively comprehensive in terms of content area, and also provided high-quality information. Most websites provided information on the symptoms of dementia, its natural progression, and an overview of treatment options. However, the benefits versus risks of treatment, the course of illness without treatment, and other issues, such as driving safety and caregiver support networks, were less commonly addressed. The quality of information provided on

TABLE 3.
Canadian dementia websites evaluated

<i>Name</i>	<i>URL</i>	<i>Google Page Rank using "Dementia"</i>	<i>Google Page Rank using "Alzheimer"</i>
1. Body + Health	http://bodyandhealth.canada.com	1	7
2. Dementia Guide	http://www.dementiaguide.com	2	--
3. Dementia Journey	http://www.dementiajourney.ca *	5	--
4. Toronto Dementia Network	http://www.dementiatoronto.org	8	--
5. Veteran's Affairs Canada: Dementia and Alzheimer Disease	http://www.veterans.gc.ca/eng/sub.cfm?source=health/dementia **	12	59
6. Alzheimer's Society of Canada	http://www.alzheimer.ca	22	1
7. Alzheimer's Foundation Caregiving	http://www.alzfdn.ca	--	6

* Website is now found at: www.alzheimerbc.org/Living-With-Dementia/Dementia-Journey.aspx

** Website is now found at: www.veterans.gc.ca/eng/health/dementia

websites varied, although there were some websites which presented relatively high-quality information that might be most helpful to PWD and their caregivers. Three websites in particular (www.alzheimer.ca, www.dementiajourney.ca, www.dementiaguide.com) could be recommended by health-care professionals to PWD and caregivers as resources for information about many common topics related to dementia.

The provision of accurate information for persons with dementia and their caregivers is an important area frequently identified as an unmet need for individuals recently diagnosed with dementia. Persons with dementia and their caregivers often seek self-education about the disease and its management through written materials,⁽⁶⁾ and are (as one caregiver stated) "constantly trying to read any literature I can get".⁽³⁾ However, qualitative studies have found that PWD and their caregivers often express a lack of information provided by their primary care providers^(3,4) and receive little direction with regard to finding appropriate literature.⁽⁵⁾ Consequently, many caregivers are left feeling ill-equipped in terms of knowledge and skills following the disclosure of a diagnosis.⁽³⁷⁾ In turn, caregivers try to self-educate and seek out information on their own.^(37,38) Given the complexity of dementia, the information needs are broad. Caregivers have expressed the need for increased information regarding tests for diagnosis,⁽³⁷⁾ medications⁽³⁷⁾ and treatment options,⁽⁷⁾ disease progression^(7,37) and prognosis,⁽³⁹⁾ as well as guidance on behaviours.⁽⁴⁰⁾ Caregivers have also expressed the need for information regarding financial assistance and legal advice,⁽⁴⁰⁾ as well as support services.^(7,39) Our review of Canadian websites for AD suggests that some websites may be able to address many of the information needs identified by PWD and their caregivers. Although some websites are of relatively high quality and comprehensive, there is further potential to improve the information provided on websites.

Despite the widespread use of the Internet as a source of health-care information,^(11,13,15,23) to date there have been

relatively few studies of websites for AD. Two previous studies have examined the quality of information provided on dementia websites with evaluations employing various scales.^(25,26) The first study evaluated 13 Korean websites in terms of construction, operation, accessibility, and content, each on a four-point scale.⁽²⁶⁾ The breadth of information provided was found to be low across the websites and the appropriateness of the content was found to range from low to high. The second study aimed to assess quality with regard to content, credibility, and utility of 16 frequently accessed websites using the Dementia Caregiving Evaluation Tool.⁽²⁵⁾ Similarly, the quality of information provided on websites from this study was found to range from low to high, with scores from 27.36 to 96.03 out of a possible 100 points. While we were not able to compare our results against those of previous studies, our results are consistent with regard to the variation in the quality of information provided on the dementia websites that we observed in our review. This indicates that issues related to the quality of information provided both to caregivers and individuals with dementia are not limited to Canadian websites.

Our study has relevance to organizations that provide information and resources for PWD and their caregivers in Canada. First, it is important for website administrators to optimize their websites for common search engines such as Google. For example, individuals from the public attempting to identify information about Alzheimer's disease who used the search term dementia may not easily identify the Alzheimer Society of Canada website as this website only appeared on the third search engine results page when the term "dementia" was used as a search term. Including the terms dementia and Alzheimer within the webpage characteristics may make it easier for some websites to be identified by users. Similarly, PWD or caregivers may be able to identify a broader range of potentially relevant websites by searching for both dementia and Alzheimer when attempting to find online resources.

TABLE 4.
Assessment of dementia website content compared to Canadian Consensus Guidelines on the Diagnosis and Treatment of Dementia

<i>Dementia Guideline Topics</i>	<i>Body + Health</i>	<i>Dementia Guide</i>	<i>Dementia Journey</i>	<i>Toronto Dementia Network</i>	<i>Veteran's Affairs Canada:</i>	<i>Alzheimer Society</i>	<i>Alzheimer's Foundation Caregiving</i>	<i>Number of Websites Providing Content (%)</i>
Difference between mild cognitive impairment, normal aging and dementia	Y	Y	Y	N	N	N	Y	4 (65)
Symptoms and associated features of dementia	Y	Y	Y	Y	Y	Y	Y	7 (100)
Different types of dementia	Y	Y	Y	Y	N	Y	Y	6 (86)
Role of cognitive testing in evaluating dementia	N	Y	Y	Y	N	Y	Y	5 (71)
Utility of neuroimaging in diagnosing dementia	Y	Y	Y	Y	N	Y	Y	6 (86)
Disclosure of diagnosis to the patient with dementia	N	Y	Y	N	N	Y	Y	4 (57)
Evidence to support non-pharmacological treatments	N	Y	N	Y	N	Y	Y	4 (57)
Prognosis and natural progression of dementia	Y	Y	Y	N	Y	Y	Y	6 (86)
Cholinesterase inhibitors: benefits, side effects, duration of treatment	N	Y	Y	N	N	Y	Y	4 (57)
Memantine	N	Y	Y	Y	N	Y	Y	5 (71)
Behavioral symptoms associated with dementia	N	Y	Y	Y	N	Y	Y	5 (71)
Community resources with specific mention to Alzheimer Society	N	Y	Y	Y	Y	Y	N	5 (71)
Impact of dementia on driving	N	Y	Y	Y	N	Y	N	4 (57)
Caregiver support networks	N	Y	Y	Y	Y	Y	Y	6 (86)
Assessment and management of caregiver stress	N	Y	Y	Y	N	Y	Y	5 (71)
Genetic risk factors	Y	Y	N	Y	Y	Y	Y	6 (86)
Total Number of Dementia Guideline Topics Addressed, N (%)	6 (63)	16 (100)	14 (88)	12 (75)	5 (31)	15 (96)	14 (88)	

TABLE 5.
Quality of information provided on Canadian dementia websites according to the DISCERN instrument

<i>DISCERN Domains</i>	<i>Body + Health</i>	<i>Dementia Guide</i>	<i>Dementia Journey</i>	<i>Toronto Dementia Network</i>	<i>Veteran's Affairs Canada</i>	<i>Alzheimer Society</i>	<i>Alzheimer's Foundation Caregiving</i>	<i>Websites with DISCERN Domain Score ≥ 3 N (%)</i>
Explicit Aims	1	4.5	5	3.5	3	4	5	6 (86)
Aims Achieved	1	4	4.5	4	2.5	5	4	6 (86)
Relevant to consumers	2.5	4	5	3	2.5	5	4	5 (71)
Make sources of information explicit	1	3.5	4	4	2.5	2.5	3	4 (57)
Make date of information explicit	1.5	4	3.5	4	3.5	3	3	6 (86)
Be balanced and unbiased	2.5	3	4.5	5	3	4.5	3.5	6 (86)
List additional sources of information	1	5	5	5	4	4	3.5	6 (86)
Refer to areas of uncertainty	2	3.5	4	3	2.5	4	3.5	5 (71)
Describe how treatment works	1.5	4.5	5	1	1	5	2	3 (43)
Describe the benefits of treatment	2	4	4.5	1	1	4	2	3 (43)
Describe the risks of treatment	1	4	4	1	1	4	1	3 (43)
Describe what would happen without treatment	1	2.5	1.5	1	1	2	2	0 (0)
Describe the effects of treatment choices on overall quality of life	1	4	1.5	1	1	2.5	1	1 (14)
Make it clear there may be more than one possible treatment choice	2	5	4.5	3	1	4	2.5	4 (57)
Provide support for shared decision-making	1.5	5	5	2.5	1.5	4.5	3	4 (57)
Overall quality of the publication as a source of information about treatment choices	1	4	5	3	1	4.5	3	5 (71)
Total Number of DISCERN Domains with Average Score of ≥ 3, N (%)	0 (0)	15 (94)	14 (88)	10 (63)	4 (25)	13 (81)	10 (63)	--
DISCERN Total Score, Mean (SD)	23.5 (2.1)	64.5 (10.6)	66.5 (0.7)	44 (11.3)	32 (9.9)	62.5 (9.2)	46 (17.0)	--

N = number, SD = standard deviation.

Our study also identified that, with the exception of a single website, none of the websites provided information on some of the more common topics that are frequently of interest to PWD and caregivers. Organizations providing information about dementia could, therefore, either improve upon the content that they provide on their websites or provide links to other websites where this information is provided. Finally, all the websites in our review had limitations in the quality of the information on their websites and additional information could be provided to improve the quality of this information.

There are some limitations to our study. Although we assessed whether information relevant to dementia was present on websites, there are other aspects of the websites which are also important but were beyond the scope of the present study. Our selection of content areas was based on our review of the literature on the general information needs of PWD and caregivers. The actual topics of interest identified by PWD and their caregivers that they would prefer to have available on websites may include additional subjects which were not assessed in our review. In the future, it would also be important to assess whether the information currently provided on websites was deemed to be useful and easily accessible by PWD and their caregivers. The use of only two evaluators and the relatively small number of websites evaluated may have contributed to the only moderate estimates of inter-rater reliability observed in our study. There were also only a few websites that we identified using our search strategy and it is possible that our search overlooked additional AD websites from Canada although, given our pragmatic search strategy, it is unlikely that any additional websites would be frequently accessed by PWD or their caregivers using typical Internet search strategies. Also, we only evaluated websites from Canada and so our findings may not generalize to websites originating from other countries. We also did not assess how “user-friendly” individual websites were, which may be particularly important in making Internet-based information accessible for PWD,⁽⁵²⁾ and we did not assess the reading ability required for users to access information, which could limit the usefulness of Internet sources for individuals with lower education or language comprehension.⁽²⁴⁾

There are some potential strengths of our study. First, we used Canadian dementia guidelines to assess the content of websites which allowed for a direct comparison between best practices in dementia care and website content within Canada. Although these results from our study apply directly to the Canadian guideline recommendations and Canadian websites, the websites that were reviewed in our study will likely also be useful to practitioners, PWD, and caregivers in other regions as most of the guideline recommendations are not specific to the Canadian setting. We also used a validated and reliable measure of website quality which should facilitate a valid assessment of the quality of the reviewed websites.

CONCLUSION

In conclusion, this study of the content and quality of Canadian dementia websites found that there are some high-quality and relatively comprehensive websites that may be recommended to PWD and their caregivers which would help to provide them with important information. Organizations and developers of websites for individuals with dementia should involve stakeholders and health-care providers to ensure that the content that included in these websites is scientifically valid and clearly written, and that it addresses the topics that might be of most importance to the end-users of this information. Knowledge tools for health-care professionals would help them provide information to patients and families on credible websites for the growing population of older adults with AD in Canada.

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CONFLICT OF INTEREST DISCLOSURES

The authors have no conflicts of interest to declare.

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