Exploring interface design to support caregivers' needs and feelings of trust in online content



Journal of Rehabilitation and Assistive Technologies Engineering Volume 7: 1–14 © The Author(s) 2020 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/2055668320968482 journals.sagepub.com/home/jrt



Thana Hussein¹, Preet K Chauhan², Nicole K Dalmer³, Frank Rudzicz⁴ and Jennifer Boger^{1,5}

Abstract

Introduction: Family caregivers of people living with dementia require a range of accurate, current, and reliable information throughout the care trajectory. Much of this information is available online, however it can be difficult for caregivers to identify and decide what content is relevant to them. Little is known about how online design cues impact family caregivers' decision to assess how trustworthy information is and whether to engage with it.

Methods: Our exploratory research focused on the interface design of CARE-RATE, an online search tool intended to support more effective information searches for family caregivers seeking dementia care-related resources. Data from focus groups were coupled with design literature to inform the development of three mockups that were evaluated by seven dementia caregiver experts.

Results: Participants preferred a search bar design because of its simplicity, familiarity, and functionality. Design elements that impact trust included logos from reputable organizations, transparency of content author, and ratings from other caregivers.

Conclusion: Feelings of trust regarding information, including the ability to ascertain trustworthiness, is a major aspect of caregivers' willingness to engage with online content. Transparency and familiarity appear to be key elements that impact caregivers' trust in online information, which agrees with current web design research.

Keywords

Interface design, online information, dementia, trust, family caregivers

Date received: 31 January 2019; accepted: 15 September 2020

Introduction

Sixty-one percent of the 431,000 Canadians living with dementia age at home,¹ mirroring trends seen around the world.² The opportunities afforded to an older adult living with dementia in the community are significantly impacted by the willingness and ability of family members and friends to "assume, master, and maintain the caregiving role."³ The increasing prevalence of Alzheimer's disease and related dementias (ADRD) coupled with an increasing normalization of aging in place is translating into an increasing dependence on family and friends to assume the role of caregiver.

The majority of people living with dementia receive some form of care from family members,^{4,5} who negotiate a multitude of care-related tasks and responsibilities. To accomplish these tasks, caregivers seek out accurate, current, and trustworthy information to guide and support the changing contexts and needs of themselves and the person they are caring for. This information is essential as it includes tools for coping, solving problems, and dealing with uncertainty through knowledge, support, and affirmation.^{6,7}

While there is a plethora of information available online, caregivers may not have the tools, abilities, or

⁴Department of Computer Science, University of Toronto, Toronto, ON, Canada

⁵Research Institute for Aging, Waterloo, ON

Corresponding author:

Jennifer Boger, SYDE E5 6th floor, 200 University Ave. W., University of Waterloo, ON N2L 3W8, Canada. Email: jboger@uwaterloo.ca

Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (http://www.creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us. sagepub.com/en-us/nam/open-access-at-sage).

¹Department of Systems Design Engineering, University of Waterloo, Waterloo, ON, Canada

²Department of Psychology, Wilfrid Laurier University, Waterloo, ON, Canada

³Department of Health Aging & Society, McMaster University, Hamilton, ON, Canada

time to find what they are looking for.⁸ There is a growing number of social media, internet sites, and mobile applications that offer resources and information. Online information is doubling in size every two years, with the cumulative amount of data expected to increase to 44 zettabytes by 2020.9 Finding reliable online information requires careful and thoughtful attention in searching for and identifying what is relevant and authentic. This requires time, effort, and knowledge of how to perform an effective search as well as how to then filter through the results. The process of searching for relevant information in online environments has been reported as a significant contributing factor of caregiver stress,¹⁰ which can lead to burnout and other unwanted consequences for health and wellbeing for both the caregiver and the care recipient. Moreover, it can be difficult for caregivers to ascertain the legitimacy of the sources that they find. The ability for an internet user to effectively find information relies on technologies' ability to succinctly and accurately deliver information as well as the user's ability to access and interpret it. Indeed, a noted limitation of web-based caregiver-focused programs lies in the challenges caregivers encounter as they attempt to adopt and/or make correct or most efficient use of them.^{11,12}

In response to these challenges, we are developing CARE-RATE, an online tool that uses natural language processing and artificial intelligence to search the web for dementia care-related resources using context-specific information extracted from the search that was performed. The initial development of CARE-RATE has involved consultation and crowdsourcing with caregivers to create a tool that is designed to meet caregivers' needs; this includes the systematic investigation and creation of a user interface that complements caregivers' abilities, perceptions, and preferences. To date, little work has investigated the relationship between interface design and assessments of trustworthiness for caregivers; to our knowledge, no research has been done to explore what design cues impact assessments of trust and source selection for dementia-related resources. We seek to bridge this gap by systematically investigating the design elements that could enable family caregivers to estimate their perception of the trustworthiness of search results more readily.

Literature review

Caregivers' online information-seeking practices

Family caregivers are increasingly encouraged and expected to access and make sense of information as a means to guide and support their role.¹³ A cross-

country survey of Canadian family caregivers performed by Dubrack revealed a commonality of information needs, including: pain management, navigating a complex health care system with a variety of uncoordinated services, bereavement support, respite, practical caregiving information, what to expect as the illness progresses, dealing with various members and actors of the professional and volunteer care team, legal and financial questions, emotional and spiritual support, and complementary and alternative therapies.14 Research has also shown family caregivers require information that is designed to meet their unique needs, that is, information that is individualized, timely, and understandable.¹⁵ Furthermore, caregivers' information needs will evolve over the short and long term. Providing quality care within this dynamic context requires accessible information that is responsive to the family caregivers' needs at these different points in time across the caregiving trajectory.¹⁰

Accessing conventional services and resources can be difficult for caregivers due to time and financial constraints.^{16,17} Kim, Powell, and Bhuyan reported that family caregivers commonly use the internet to seek out health information regarding dementia and steps for providing effective care for loved ones.¹⁸ Internet-based care sources can encourage users to become more proactive as consumers of healthcare contributing to a healthier well-being,¹⁹ higher-levels of confidence in decision-making, increased feelings of self-efficacy, as well as an overall more positive demeanor towards providing care.²⁰⁻²² However, caregivers who are 65 and older often have more limited health literacy or e-health literacy experience, which results in disparities in health and access to health care resources, including online sources. This reduced access may in turn obstruct their decision-making abilities.23,24

A series of three in-depth literature reviews focused on web-based programs for family caregivers of older adults living with dementia revealed that online interventions have particular features, including: offering multiple parts, being psychoeducational in nature, and having the ability to be customized by including (or ignoring) different components of the intervention.^{25–27} While each of these features necessarily inform the online program's design and development, what remains unknown is how the design of these features determine the degree to which family caregivers trust the information found on these online interventions. In light of this gap, the development of CARE-RATE both builds on and departs from existing research in this area to not only create an interface that complements caregivers' abilities and preferences but that explicitly enables family caregivers to more easily assess their trust in the results provided.

The internet can feature heavily in family caregivers' everyday lives, delivering healthcare interventions and services. It is imperative, however, to consider the additional online information that caregivers seek beyond health-related regimens. Morris and Thomas²⁸ and Barnes and Henwood²⁹ discuss the more holistic contexts of caregivers, acknowledging that the relationship between the care recipient and the caregiver, including social and affective characteristics, may influence information use in addition to the more traditionally assumed and discussed influences of the progression of the illness. As caregivers' information environments become increasingly decentralized and diffused, particularly as more information is available online, caregivers' information needs must be understood within their broader care contexts.^{30,31} Caregiver-focused information interventions must take into account caregivers' dynamic contexts, including caregivers' changing knowledge base, their changing information needs and abilities, the available resources that can be accessed, and the changes to the caring relationships within which they live. Moreover, all this must be conveyed to them in a way they can understand, access, and put to use.

Web design and trust

Designing for credibility and trust in technologymediated interfaces has been well studied and is of increasing importance in human-computer interactions.³² Perception of credibility inversely influences perception of risk; if a website is viewed as credible, it can be assumed that interacting with it will entail a lower risk.³³ Given the stakes of the information sought and accessed, caregivers are on average more vigilant about the websites they engage with. Information content, navigation capabilities, and web design (including graphics and images) all play a role in the degree to which caregivers trust a website.³³ Pursuing information online and arbitrating credible source, can be a challenging task; this is especially for dementia caregivers due to factors including stretched resources, limited time constraints, and exhaustion.^{16,17} Additionally, dementia caregivers are encountering elevated levels of stress, increased intensity of care provision, and diverse health problems covering a range of physical, psychological, social, and financial facets.^{34–36}

A website's ease of use also influences its credibility, as users perceive easy-to-use websites as being more predictable and honest.³³ Caregivers who are seeking information on a website that is easy to use will experience a lower cognitive burden, leaving them with more cognitive resources that can be used to attend to credibility cues.^{37,38} Reputation systems, including recommender systems, collaborative filtering, or social navigation, aid in trust arbitrations.^{39–41} Aggregated ratings provide a meaningful history that can be used by other people to judge the risk of a transaction or the value of information from a given provider.^{39–42} Trust in a mechanized recommender can be increased by a colloquial interface and disclosure of what the recommender system knows about the user.⁴²

Trust is another concept that significantly impacts one's perception of online information. Trust incorporates the discernment that a person has vulnerabilities and those susceptibilities could be infringed or capitalized upon.⁴³ Vulnerability, with the simultaneous probability of exploitation, should likewise, be explored when designing a trustworthy interface for dementia caregivers. Dalmer⁴⁴ identified that information completeness,45 listings of author credentials,46 homophily,⁴⁷ and hosting by reputable or expert organizations⁴⁸ were all qualities that increased individuals' trust in and perceptions of reliability in health websites. A vital dimension of trust in online and offline sources is expertise, with many turning to online experts to augment their own knowledge base.46,49

Website design elements including layout, colour, and navigation all impact trust.⁵⁰ Impressions of trustworthiness increases when websites are visually appealing, meaning they feature a balance of colour, graphics, and text, making use of visual design elements such as incorporating professional images of products and exhibiting content that is free from any typographical and grammatical errors.^{38,51} While some studies revealed that users may find sites more trustworthy if they feature a third-party trust logo (also referred to as "seals of approval"),^{51–55} others uncovered that users either do not notice the presence of such logos or do not care,^{38,56} possibly because they do not find any credibility in them given the ubiquity of websites that disseminate false information.

This paper builds on the scant number of studies that explicitly report on the adoption of usability testing or the integration of a user-centered design approach in the development of their web-based programs created for caregivers of individuals living with dementia.^{57,58} To our knowledge, this is the first published work that focuses on building a tool that assists with source selection and assessing cues that impact caregivers' feelings of trust of online dementia-related resources throughout a user-centered design approach. The remainder of the paper focuses on the development of an interface for the CARE-RATE search system, highlighting our goal of incorporating design elements that support family caregivers' navigation of and trust in online information resources.

Care-RATE's initial development

The initial development of CARE-RATE leveraged information from two sources: 1) focus groups with caregivers of people living with dementia; and 2) themes from peer-reviewed literature.

Focus groups

In order to assess user needs, abilities, and expectations required for CARE-RATE, we conducted two inperson focus groups with five participants in each group and four over the phone interviews with dementia caregivers from the community.^{59,60} These focus groups were composed of seven women and three men, and their age ranged from 40 to 89 years old. All participants had at least one year of experience caring for a family member or friend with dementia who lives at home.

These focus groups identified three key areas where caregivers desire more online support, which were used to guide the overall functional development of CARE-RATE: 1) the ability to learn more about a specific topic; 2) finding strategies and advice from trusted sources to help them with a current concern; and 3) connecting with other caregivers. We also established an advisory committee of seven members (four current caregivers, two Alzheimer Society staff members, and a Director of retirement living and long term care) to engage in a collaborative design process.

Peer-reviewed design literature

While web-based interventions are lauded for the flexibility, convenience, and accessibility they afford family caregivers,^{61,62} interface design majorly influences adoption and acceptance.⁶³

We sought out peer-reviewed literature regarding best practices for building online interfaces for caregivers and older adults. Older adults were targeted because many caregivers are older adults and interfaces that are usable by this population are usually considered usable by younger age groups as well. This literature search resulted in the following three main design insights:

- 1. Easy to understand: To reduce frustration levels, minimize the caregiver's memory load, and reduce the overall cognitive load, we aimed to implement visible objects, actions, and options, as well as a clear, easily-retrievable instructions for the use and navigation of the system.^{64,65}
- 2. Easy to identify and distinguish interface elements: Having an easily identifiable and predictable design reduces the amount of time required to use the website,^{64,65} which is important to the caregiving context

as their time is often a scarce commodity.^{8,16,17} Adopting these design practices can assist caregivers with task completion, efficiency, and satisfaction.

3. Provide a sense of security: The trust that a website engenders plays a major role in the user experience for caregivers of people with dementia since they frequently struggle with discerning accurate and trustworthy online information.^{59,60} A good interface is one that provides a sense of security and supports the user in making safe and informed decisions.

Grounded by these main insights, we then explored the literature for a variety of interface design elements and usability heuristics⁶⁴ to incorporate into CARE-RATE's initial mockups. A summary of these elements are found in Table 1, which is a blend of recommendations for older adults and the general public.

Care-RATE mockup development

Based on information we gathered from the focus groups, the literature (regarding best practices for building online interfaces for caregivers and older adults and web design and trust), and the interface design elements highlighted in Table 1, we leveraged the parallel design process to explore several creative design possibilities for CARE-RATE. The parallel design methodology produces better outcomes^{76–78} by generating diverse ideas (i.e., the chatbot, search bar, and tree structure designs depicted in Figures 1 to 3) and ensuring that the best ideas from each design are integrated into the final concept. We also drew on Adam's work on online information reliability⁷⁹⁻⁸² where she purports that reliability, as it relates to information, is composed of three components: (1) the technical components of websites and Internet-based applications, (2) information content, and (3) expected end-user behavior. As such, our mockups considered not only the technical components, but were also mindful of caregivers' behaviours as they engaged with the content that each of the designs facilitated.

The chatbot design (Figure 1(1) to (5)) identifies the user's needs through a turn-based conversation. This interface design determines what the user needs by extracting key information from what they share with the chatbot. The intention is for the chatbot's prompting questions to be friendly and conversational so that the users can feel comfortable.

The search bar design (Figure 2(1) to (4)) enables users to have more autonomy over the information they obtain from the CARE-RATE website. As caregivers input the initial search query, the system uses natural language processing to narrow down the initial search by asking additional related "yes/no" questions.

Table 1. Interface design elements inco	rporated into CARE-RATE's initial I	nockups.
Design insight	Interface design element	Supporting literature
Easy to identify and distinguish interface elements	Adjustable font size	Very small font sizes can be difficult to read depending on visual ability and larger font sizes can lead to an increase in eye movements, resulting in loss of reading efficiency and visual fatigue. ^{65,66} Optimal font size for seniors can vary based on personal preferences and needs and thus should be adjustable. ^{65,67,68}
Easy to identify and distinguish interface elements	Sans-serif font	Sans serif fonts such as Arial are more easily interpreted by seniors. ^{65,68}
Provide a sense of security	Ask only what's necessary	Avoid asking sensitive information such as the user's home address and health conditions (if possible). If personal information is necessary to enhance the user's experience, provide an explanation and justification for why the information is needed. ⁶⁵
Easy to understand; easy to identify and distinguish interface elements	Clear data-entry field	The search box should be displayed in a position where the users would expect to find it, such as in the top right or top left corner. ⁶⁹ Fields should be clearly labeled to show what is expected because users may need guidance on what kind of data to enter into an input field. ⁶⁵ Labels and placeholders are one of the primary ways to assist users. Labels outside the input fields is reserved for vital information visible at all times, while placeholder text inside input fields is reserved for supelementary information or examples of information the user can input fields.
Easy to understand; easy to identify and distinguish interface elements	Clear headings	Topic headlines should be clear and visible and indicate the content coherently. ⁶⁸
Provide a sense of security	Complimentary word usage	Provide content, functionality, or questionnaires that accommodate older adults, but avoid wording that makes seniors feel different (e.g. avoid phrases such as "the elderly" and "disabilities") or at a certain life stage.
Easy to understand; easy to identify and distinguish interface elements	Distinguish visited sites from unvisited sites	Users, especially those with challenges to their short-term memory, may have trouble remembering which sites they have already visited. If users experience difficulty discerning differences between links, they may inadvertently repeatedly return to the same pages, ultimately causing frustration and reduced sense of mastery when the sites fail to meet their needs. ⁷² Web design practices and hypertext theory all indicate the need to change link colours to help users distinguish between sites they have or have not visited. ⁷²
Easy to identify and distinguish interface elements	High brightness and colour contrast	Older user's need higher brightness levels to distinguish colors. ^{65,73} Therefore, using a negative contrast displays (where the text is darker than the background) could be helpful for avoiding issues with glare. ^{65,68}
Easy to identify and distinguish interface elements	Use color sparingly	Color should be used to convey information or to distinguish areas of the screen. Bright and/or saturated colors should only be used to guide individuals where to look. ⁷³
Easy to understand; Easy to identify and distinguish interface elements	Large targets	Make buttons and links big enough for users to click. It is recommended that click targets should accept clicks in an area spanning at least 11 millimeters diagonally. ⁶⁵
Easy to understand	Consistent navigation and interactive elements	Ensuring consistently throughout the interface improves learnability and reduces frustration. ^{74,75}
Easy to understand; easy to identify and distinguish interface ele- ments; provide a sense of security	Mark ads clearly	Throughout website and search results, ensure that users can easily tell which items are paid- for-placement items and which are not. ⁶⁵
Easy to identify and distinguish interface elements; provide a sense of security	Target Spacing	Provide blank space around clickable targets, and between questions and answer boxes. This allows users to easily hit their desired targets and avoid hitting other targets unintentionally. ⁶⁵

CR	CARE-RATE
	Hello! What can I help you with today?
Reply	

Hi, Welcome to CARE-RATE!

CA

Hi, Welcome to CARE-RATE!

CARE-RATE is an interactive system than can help you find information you need.

CR	CARE-RATE Hello! What can I help you with today?		
	Care Giver CG		
	I'm feeling a bit weary and lonely nowadays. I want to connect with other caregivers.		
Reply			

Hi, Welcome to CARE-RATE!

CARE-RATE is an interactive system than can help you find information you need.

Hi, Welcome to CARE-RATE!

CARE-RATE is an interactive system than can help you find information you need.

I'm feelir I want to	Care Giver CG ng a bit weary and lonely nowadays. connect with other caregivers.	Online In person		
CARE-RATI How are you Online	E looking to connect with people?	CARE-RATE Airight, I just need to ask you a few questions first to narrow down the search. What is your postal code?		
Reply		Care Giver CG T9K0G4 Reply		
	SEND	I don't want to share SEND		
	CARE-FACE Sounds great. Here are some results related to the search: In person programs for dementila caregivers near Waterloo ON Saturday Brunch Club @ KW Dementi Average Rating among care givers Forming una notification of these set obliver images a figure. Une the direct events of the search images a figure events of the se			
	Counselling & Therapy Average	Rating among care givers 🛛 🗶 🛧 🗶		
	Lorem (psum dolor sit annet, consectetur adpiscing elt, sed do eiusmod tempor incidiauti ut labore el dolore magna aliqua. U enim ad minim veriani, que nostrud executation utamoc laboris nia ut aliquip ex ea commodo consequat. U enim ad minim venant, que in oncluid executation utamoc laboris niai ut aliquip ex ea commodo consequat.			
	Dementia Husbands Association Average F	Rating among care givers : 🎽 🜟 🌟		
Lorem ipsum dobr sit amet, consectetur adjuscing eiit, sed do eiusmod tempor incididunt ut labore et dobre magna aliqua. Ut entim ad minim veniam, quis nostrud				
	1 2	3 I can't find what I'm looking for		

Figure 1. Example of successive interactions in the chatbot design.

CARE-RATE	CARE-RATE Connecting with other caregivers
CARE-RATE is an interactive system than can help you find information you need. What can I help you with today?	"Let me filter down the results for you" How would you like to connect with caregivers? Online In person
Search	
	CARE-RATE Connecting with other caregivers
	"Here is what I found for: In person programs for dementia caregivers near Waterloo ON"
	Saturday Brunch Club @ KW Dementia Average Ruling among care givers
"Let me filter down the results for you"	Loom tourn dans dans dans dans dans dans dans dan
	Counselling & Therapy Average Rating among care givers 🛛 🌟 🌸 📩
How would you like to connect utilit caregiver? Costine It person It person	Lever sound-dore if arm consenting addication of the other sound intervent of the other sound intervent of the other sound and the other other sound and the other sou
What is your postal code?	Dementia Husbandis Association Average Rating among care givers 😐 📥 🌜 😒
T7W0M Send I don't want to share	Lawer beam door at amit, constanting and a door at advanced tempor indicative at advance at advance and advance and advanced and advanced advance
	1 2 3 I can't find what I'm looking for

Figure 2. Example of successive interactions in the search bar design.

As the user answers the filter questions, the results are updated to match the refined search.

The tree structure design (Figure 3(1) to (5)) allows users to narrow down their search terms by choosing one of two to three options provided by CARE-RATE for a successive series of questions. The searching actions in this design are guided by the computer, which is intended to significantly minimize cognitive burden/effort from the user.¹

All three mockups are intended to prompt friendly and conversational questions to help users to feel comfortable throughout the searching process. The options are written in first person, making it easier for the user to quickly identify the questions related to their needs. As shown in Figures 1(4), 2(3), and 3(4), each design gives the user the choice to refuse to share certain sensitive information, such as their home address, providing the user with a sense of control over their privacy and security. The search results (as seen in Figures 1(5), 2(4), and 3(5)) show ratings provided by other caregivers, further supporting the user's judgement regarding the security and trustworthiness of the information provided. The font used in each design is sans serif and the font size is adjustable. The background is white and the text is black to provide high contrast between important user interface elements and make the textual content easily identifiable.

Care-RATE mockup evaluation

The CARE-RATE advisory committee was consulted through a randomized, mixed-methods semi-structured interview process to determine a preferred design and to identify first impressions, preferences, and changes that could be made to improve trust. The study was reviewed and approved by the University of Waterloo Office of Research Ethics (ORE # 22230) and all participants were treated in accordance with Tri-Council's Policy on the Ethical Conduct for Research Involving Humans (TCPS 2).

Seven advisory committee members participated in providing feedback for the three initial CARE-RATE mockups. Six interviews were conducted over Skype and one participant was unable to take part in the interview over Skype due to time constraints, and therefore completed the questionnaire independently and returned it electronically via email.

Prior to the study, participants were emailed a PDF document with screenshots of the different interfaces presented in a randomized order. The instructions in the email asked the participant not to look through the PDF document before the interview in order to preserve their first impressions of the designs. Interviews were conducted over Skype, with participants sharing their screen with the interviewer. Participants were asked questions about their preferred mockup, general



Figure 3. Tree structure design.

design feedback, and perceptions regarding system trustworthiness. The interview took approximately one hour to complete and was audio recorded for post-session analysis. The interviews were transcribed and coded for analysis.

Results

The advisory committee included four participants who were currently caregivers of someone living with dementia, a Director and a staff member from the local Alzheimer Society, and a Director of retirement living and long-term care facility. The group of caregivers had a range of care experiences: one caregiver was providing long distance care to his mother in United Kingdom while he resides in Canada, another caregiver was providing care to a wife who had earlyonset Alzheimer's disease, another was a young carer taking care of her mom while being a University student, and one caregiver was assisting her husband with dementia. All members of the advisory committee were comfortable with using technology and took part in the survey remotely via Skype. The diversity of experiences among the caregivers in addition to the advisory committee allowed CARE-RATE to be tested from various perspectives.

Data analyses were mainly qualitative and involved descriptive statistics (e.g., counts) because of the small

sample size and the ethnographic nature of the study. This approach is comparable to other early stage research in prototype development.⁸³

Six of the seven participants rated the search bar as their preferred design; one participant rated both search bar and the tree structure design as tied for their favourite. No participant rated the chatbot design as their most preferred. Participants liked the search bar for its simplicity, perceived ease of use, feeling of familiarity, and found it to be the most appealing design. One participant specifically commented on appreciating the simple look of CARE-RATE: "minimal [referring to CARE-RATE], sites like Facebook are too busy, too many places people can click by accident ... good to see that there's only one place a person can go [referring to CARE-RATE's search bar]". The preference and feelings of familiarity for the search bar design were likely heavily influenced by its similarity to the interface design of other search engines on the internet.

The tree structure design was appreciated for offering suggestions to those who did not know what they were looking for, which was the intent of the design. One participant specifically mentioned that the question format of the design gave them new ideas to search for information: "[Tree structure design] primed me to choose questions I have never thought about before." Participants also reported that this design appeared to be easy to navigate, easy to learn, visually trustworthy, and they indicated that they would be very likely to use this tool to look for information if they encountered this design on the internet.

The chatbot design was least preferred by participants. Uncertainty around whether the chatbot was managed by a human or a computer on the other end was one of the primary reasons for participants' decreased preference for this design, contesting the third design insight of fortifying trust. Specifically, one participant viewed the chatbot design as asking someone for information and feeling limited by the information they would receive back: "[I] prefer to look for information myself rather than asking someone ... [or] maybe I just want to scan a website for information." However, despite being the least popular of the three designs, participants still appreciated the simple and uncluttered look of the design, confirming the importance of simplicity in design preference by older adults.

Participants expressed interest in the CARE-RATE interface's ability to save past searches, which aligns with previous literature that indicates the need for users to be able to identify websites that they have visited versus the websites they have yet to visit.⁶⁰ Participants also spoke to the importance of using user-friendly language on this website, providing

further evidence for Johnson and Finn's suggestion to use complimentary language in technologies for older adults.⁶⁴ Furthermore, CARE-RATE only asked for information that is necessary to conduct the search (e.g., stage of dementia, age of person with dementia) and participants valued having the option to decline not sharing their postal code, an important aspect of building trustworthy platform for older adults.⁶³

Participants were asked to choose between four colour schemes: red, orange, green, and purple. Green and purple were the most preferred as two participants associated green with traffic lights and said "green means go" and purple was also preferred as it felt soft on the eyes. Red was the least preferred as participants thought it may cause some anxiety. After receiving this feedback, we went forward with implementing the purple colour scheme into CARE-RATE, which aligns with previous studies' suggestions of having darker text on lighter background.^{64,67,72}

Several aspects of the system were identified as contributing to the trustworthiness of CARE-RATE. Participants had strong opinions regarding factors they felt influenced their perception of trust toward online sites, including navigational architecture, information content accuracy as determined by the credentials of the author and/or the author's affiliated organization, seals of approval from trusted organizations (e.g., the Alzheimer Society, University of Waterloo), branding, and a padlock symbol in the browser's URL bar to confirm the security of the webpage. Furthermore, a system where other users' ratings and reviews were visible was preferred by participants as it would facilitate best results among the caregiver community and build credibility and trustworthiness in the sources. Specifically, all participants liked the idea of using a 5-star system with the addition of having an option to expand on their rating by leaving a comment. All participants disliked the idea of thumbs up/down as a rating system as it does not provide a spectrum of options for rating nor the option to provide a justification for the rating. The preference for these features aligns with previous work of Dieberger et al.,⁴¹ Fogg et al.,⁵¹ Nielsen et al.,³⁸ and Freeman and Spyridakis.⁴⁶

Results from the advisory committee testing were used to refine the CARE-RATE search bar design, as shown in Figure 4(1). Modifications included the addition of logos from affiliated organizations on the homepage, displaying the author/organizations responsible for providing the information, and displaying ratings from other caregivers to increase system trustworthiness. We also simplified the design of the filter questions by placing them on the left side and increasing the size of the buttons to enhance the navigational architecture and to improve ease of use.



Figure 4. (1) Search bar design modification (homepage). (2) Search bar design modification (SERP).

Discussion

Results from the evaluation of three different mockups reinforces caregivers' need for simplicity and ease of use when searching online information. While their preferences do not appear to differ radically from those of older adults in general as reported in the literature, the participants had a strong desire for high levels of transparency and perceived authenticity of information for both CARE-RATE as well as the ability to ascertain the credibility of the websites it displays in the search results.

Findings from the advisory committee aligned with the three main design insights that were used to create the mockups: 1) easy to understand; 2) easy to identify and distinguish elements; and 3) provide a sense of security. The similarity of this design to other existing search tools also allowed participants to experience an easily predictable design which reduced the time required to learn how to use CARE-RATE. And, aspects such as the inclusion of logos of affiliated organizations such as University of Waterloo, were also discussed by participants as a method to enhance the sense of security and trustworthiness when using CARE-RATE.

The modified (final) version of the CARE-RATE search bar design differs from current website designs in a few ways. First, the homepage prominently displays logos from the affiliated organizations that are building CARE-RATE (i.e., University of Waterloo, University of Toronto, and AGE-WELL NCE) to enhance user trust. While some studies^{38,56} have found that users do not notice the presence of or do not care for such logos, findings from consultation with our advisory committee revealed that users highly valued these logos as it helped them understand who was affiliated with the CARE-RATE tool.

Another unique feature is showing the name of the person or organization providing the content for each of the search results, as shown in Figure 4(2).

This information is presented below the webpage's link and above its description. As many people cannot discern the content's author from the page's URL, adding this feature could be especially useful in assisting caregivers of people living with dementia in deciding whether they wish to engage with the related content. Guided by comments from the CARE-RATE advisory committee, we also implemented a rating system that is displayed with each search result. The inclusion of these aggregated ratings is intended to assist users in trust and risk judgments, a finding that corroborates with the literature.^{39–41}

The most distinctive element about CARE-RATE's interface is the filtering system. The CARE-RATE algorithm filters results by asking users a series of questions to clarify the user's intent which subsequently displays only websites that are labeled with the categories corresponding with the answers to those questions. In our evaluation, we sought to understand how to display the filtering function on the front-end; namely, whether participants preferred to see results all at once after answering a series of questions, or whether they preferred continuously refining and loading results. Results from testing showed a preference for having the results continuously updating. This finding is in line with the literature, which has found that caregivers of people living with dementia commonly feel overwhelmed with the amount of information they need to sort through.8 Therefore, showing the users results as they add filters gives the users more autonomy and transparency in this decision-making process as they can see intermediary information during the filtering process.

Methodological considerations and future work

While the findings from this work are directional, there are limitations that should be kept in mind. First, due

to resource limitations, the focus groups and mock-up evaluations had small sample sizes and with participants residing in Canada; as a result, generalizability and representativeness may be limited and the views expressed do not necessarily represent those of the broader care community. While our advisory committee consisted of a diversity of participants (i.e., different types of caregivers, Alzheimer's Society of Canada staff, and a Director of a long-term care organization), future research needs to be done with a larger, more robust, representative sample using sound user experience research methods such as foundational concept testing to further validate CARE-RATE and iterative, evaluative usability testing to improve the design functionality.

Secondly, this research was conducted on three designs that all pertain to the CARE-RATE system. As such, interfaces for different applications or different interface designs may elicit different reactions and key themes. Lastly, though the focus of this paper pertains to interface design, there are two vital, related topics that may impact users' sense of security when navigating online information: data security and online privacy. While the CARE-RATE user interface is being built and evaluated, future research needs to be conducted in parallel to better understand how CARE-RATE's data security and privacy policy impacts users' sense of security and trust in information sought and retrieved.

Current research shows the need for a tool for caregivers to easily locate credible, current, and trustworthy information to support themselves when someone they know has been diagnosed with dementia. CARE-RATE seeks to address that need by collaborating closely with caregivers in an effort to ensure the resulting system complements what they both want and need. The next steps for CARE-RATE include working with caregivers globally through a crowdsourcing task to create (to our knowledge) the first caregiver-labelled dataset of online information. In the upcoming months, CARE-RATE will be tested with caregivers in the community prior to the deployment of CARE-RATE to the internet for testing and eventual use by caregivers around the world.

Conclusions

This research focused on the initial development of an interface for the CARE-RATE system. Our goal was to identify and incorporate design elements that support family caregivers' of people living with dementia's ability to locate credible and trustworthy dementia-related information, resources, and products on the web. The data extracted from our focus groups with caregivers of people living with dementia and design evaluation with our advisory committee have identified interface design recommendations that complement caregivers' preferences, abilities, and needs. Elements that impact trust for caregivers of people living with dementia include a simple layout, easy to use, transparency of author/ organization, and ratings from other caregivers. Thus, this exploratory research sets the foundation for our next phase of research, which includes an evaluation of the CARE-RATE system, including the redesigned interface, with a larger group of caregivers living in the community.

Acknowledgements

We would like to thank our advisory committee for their ongoing input and support. We also thank Sally Moon for her assistance in developing initial designs. Preliminary findings related to the research described in this paper were presented at AGE-WELL's 4th Annual Conference, Vancouver 2018.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was supported by AGE-WELL NCE Inc. (WP 2.3), a member of the Networks of Centres of Excellence program. The views expressed in this article are those of the authors and not necessarily those of AGE-WELL NCE.

Guarantor

JB.

Contributorship

TH, PKC, NKD, and JB wrote and edited the manuscript. TH and PKC developed the testing protocol, gained ethical approval, and conceived the study. TH and NKD researched the literature. JB and FR are the principal investigators; they mentored the research and article preparation. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

Note

 In addition to information gathered from focus groups and the available literature, we also consulted existing web-based interventions explicitly developed for family caregivers of persons living with dementia (including My Tools 4 Care⁶¹ and CARES[®] Dementia Care for Families^{TM62}). Whereas both My Tools 4 Care and CARES[®] Dementia Care for FamiliesTM are designed to enhance caregivers' knowledge as caregivers navigate the sections or modules in their web-based psychoeducational tool, we contemplated the inclusion of interactive, community-focused web-based experiences throughout the design of CARE-RATE, including a dialogue-based interface and the incorporation of caregivers' ratings and reviews of resources.

ORCID iDs

Thana Hussein **b** https://orcid.org/0000-0003-2830-8376 Nicole K Dalmer **b** https://orcid.org/0000-0002-0326-4293 Jennifer Boger **b** https://orcid.org/0000-0001-6150-151X

References

- 1. Canadian Institute for Health Information. Dementia in Canada, www.cihi.ca/en/dementia-in-canada. (2018, accessed 15 December 2018).
- 2. Evans D, Price K and Meyer J. Home alone with dementia. *SAGE Open* 2016; 6: 215824401666495.
- 3. Hepburn KW, Tornatore J, Center B, et al. Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. *J Am Geriatr Soc* 2001; 49: 450–457.
- Schulz R and Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry* 2004; 12: 240–249.
- Ward-Griffin C, McWilliam C and Oudshoorn A. Negotiating relational practice patterns in palliative home care. J Palliat Care 2012; 28: 97–104.
- McKenzie P and Dalmer N. Creating communities of care: delineating work in the information-care relationship. In: *Proceedings of the annual conference of CAIS*/ *Actes du congrès annuel de l'ACSI* (ed DH Michels, A Pollak), Calgary, Canada, 1–3 June 2016.
- Dalmer NK. Informing care: mapping the social organization of families' information work in an aging in place climate. PhD Thesis, The University of Western Ontario, London, Ontario, 2018.
- Peterson K, Hahn H, Lee AJ, et al. In the information age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatr* 2016; 16: 164–177.
- EMC Digital Universe. The digital universe of opportunities: rich data and the increasing value of the internet of things. Report, IDC Analyze the Future, April 2014.
- Wackerbarth SB and Johnson MM. Essential information and support needs of family caregivers. *Patient Educ Couns* 2002; 47: 95–100.
- Chiu TM and Eysenbach G. Stages of use: consideration, initiation, utilization, and outcomes of an internetmediated intervention. *BMC Med Inform Decis Makm* 2010; 10: 73.
- Cristancho-Lacroix V, Moulin F, Wrobel J, et al. A webbased program for informal caregivers of persons with Alzheimer's disease: an iterative user-centered design. *JMIR Res Protoc* 2014; 3: e46.

- Dalmer NK. Add info and stir': an institutional ethnographic scoping review of family care-givers' information work. *Ageing Soc* 2020; 40: 663–689.
- Dunbrack J. The information needs of informal caregivers involved in providing support to a critically ill loved one. Report, Health Canada, 2005.
- Washington KT, Meadows SE, Elliott SG, et al. Information needs of informal caregivers of older adults with chronic health conditions. *Patient Educ Couns* 2011; 83: 37–44.
- Toseland RW, McCallion P, Gerber T, et al. Use of health and human services by community-residing people with dementia. *Soc Work* 1999; 44: 535–548.
- Beeber AS, Thorpe JM and Clipp EC. Community-based service use by elders with dementia and their caregivers: a latent class analysis. *Nurs Res* 2008; 57: 312–321.
- Kim H, Powell MP, Bhuyan SS. and Seeking Medical information using mobile apps and the internet: are family caregivers different from the general public? *J Med Sys* 2017; 41: 38.
- Marziali E and Garcia LJ. Dementia caregivers' responses to 2 internet-based intervention programs. *Am J Alzheimers Dis Other Demen* 2011; 26: 36–43.
- Beauchamp N, Irvine AB, Seeley J, et al. Worksite-based internet multimedia program for family caregivers of persons with dementia. *Gerontologist* 2005; 45: 793–701.
- Powell J, Chiu T and Eysenbach G. A systematic review of networked technologies supporting carers of people with dementia. *J Telemed Telecare* 2008; 14: 154–156.
- 22. Lewis ML, Hobday JV and Hepburn KW. Internet-based program for dementia caregivers. *Am J Alzheimers Dis Other Demen* 2010; 25: 674–679.
- Sudore RL, Yaffe K, Satterfield S, et al. Limited literacy and mortality in the elderly: the health, aging, and body composition study. J Gen Intern Med 2006; 21: 806–812.
- Cutilli CC and Bennett IM. Understanding the health literacy of America results of the national assessment of adult literacy. *Orthop Nurs* 2009; 28: 27–34.
- Thompson CA, Spilsbury K, Hall J, et. al. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatr* 2007; 7: 18.
- Boots LM, de Vugt ME, van Knippenberg RJ, et al. A systematic review of internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry* 2014; 29: 331–344.
- 27. Ploeg J, Markle-Reid M, Valaitis R, et al. Web-based interventions to improve mental health, general caregiving outcomes, and general health for informal caregivers of adults with chronic conditions living in the community: rapid evidence review. J Med Internet Res 2017; 19: e263.
- Morris SM and Thomas C. The need to know: informal carers and information. *Eur J Cancer Care* 2002; 11: 183–187.
- 29. Barnes M and Henwood F. Inform with care: ethics and information in care for people with dementia. *Ethics Soc Welfare* 2015; 9: 147–163.

- Johnson JD and Case DO. *Health information seeking*. New York: Peter Lang Publishing Inc., 2012.
- 31. Barnes M, Henwood F and Smith N. Information and care: a relational approach. *Dementia* 2016; 15: 510–525.
- Riegelsberger J, Sasse MA and McCarthy JD. The mechanics of trust: a framework for research and design. *Int J Hum Comput Stud* 2005; 62: 381–322.
- Corritore CL, Kracher B and Wiedenbeck S. On-line trust: concepts, evolving themes, a model. *Int J Hum Comput Stud* 2003; 58: 737–758.
- 34. Family Caregiver Alliance. Caregiver health, www.care giver.org/caregiver-health (2006, accessed 7 April 2018).
- Lethin C, Leino-Kilpi H, Bleijlevens MH, et al. Predicting caregiver burden in informal caregivers caring for persons with dementia living at home – a follow-up cohort study. Dementia 2018. *Dementia* 2020; 19: 640–660.
- Schulz R and Sherwood PR. Physical and mental health effects of family caregiving. J Soc Work Educ 2008; 44: 105–113.
- Cheskin Research and Studio Archetype/Sapient. E-commerce trust study. Report, 1999.
- 38. Nielsen J, Molich R, Snyder C, et al. *E-commerce user experience*. Fremont, CA: Nielsen Norman Group, 2001.
- Resnick P and Varian HR. Recommender systems. Commun ACM 1997; 40: 56–58.
- Resnick P, Zeckhauser R, Friedman E, et al. Reputation systems. *Commun ACM* 2000; 43: 45–48.
- Dieberger A, Dourish P, Höök K, et al. Social navigation: techniques for building more usable systems. *Interactions* 2000; 7: 36–45.
- Zimmerman J and Kurapati K. Exposing profiles to build trust in a recommender. In: *CHI'02 extended abstracts on human factors in computing systems* (eds Tervenn L and Wixon D), Minneapolis, MN, 20–25 April 2002. pp. 608– 609. New York: ACM.
- 43. Sabel CF. Studied trust: Building new forms of cooperation in a volatile economy. *Hum Relat* 1993; 46: 1133–1170.
- Dalmer NK. Questioning reliability assessments of health information on social media. J Med Libr Assoc 2017; 105: 61–68.
- 45. Dutta-Bergman MJ. Primary sources of health information: comparisons in the domain of health attitudes, health cognitions, and health behaviors. *Health Commun* 2004; 16: 273–288.
- Freeman KS and Spyridakis JH. An examination of factors that affect the credibility of online health information. *Tech Commun* 2004; 51: 239–263.
- Wang Z, Walther JB, Pingree S, et al. Health information, credibility, homophily, and influence via the internet: web sites versus discussion groups. *Health Commun* 2008; 23: 358–368.
- Sillence E, Briggs P, Harris PR, et al. How do patients evaluate and make use of online health information? *Social Sci Med* 2007; 64: 1853–1862.
- 49. Yi MY, Yoon JJ, Davis JM, et al. Untangling the antecedents of initial trust in web-based health information:

the roles of argument quality, source expertise, and user perceptions of information quality and risk. *Decis Support Syst* 2013; 55: 284–295.

- Eysenbach G and Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *Bmj* 2002; 324: 573–577.
- Fogg BJ, Marshall JP, Laraki O, et al. What makes web sites credible? In: *Proceedings of the SIGCHI* conference on human factors computing systems, Seattle Washington USA, 2001. pp.61–68.
- Laric MV and Sarel D. Consumer (mis)perceptions and usage of third party certification marks, 1972 and 1980: did public policy have an impact? *J Mark* 1981; 45: 135–142.
- 53. Cheskin Research and Studio Archetype/Sapient. Trust in the wired Americas. Report, July 2000.
- Miyazaki AD and Krishnamurthy S. Internet seals of approval: effects on online privacy policies and consumer perceptions. J Consum Aff 2002; 36: 28–49.
- 55. Burkell J. Health information seals of approval: what do they signify? *Info Commun Soc* 2004; 7: 491–409.
- Mcknight DH, Kacmar CJ and Choudhury V. Shifting factors and the ineffectiveness of third party assurance seals: a two-stage model of initial trust in a web business. *Electron Mark* 2004; 14: 252–266.
- Hussein T, Boger J and Rudzicz F. The impact of design on feelings of trust of online information for family caregivers of people with dementia. In: *Proceedings of British human computer interaction conference*, Belfast, UK, 2–6 July 2018.
- van der Roest H, Meiland F, Jonker C, et al. User evaluation of the dementia-specific digital interactive social chart (dem-disc). A pilot study among informal carers on its impact, user friendliness, and usefulness. *Aging Ment Health* 2010; 14: 461–470.
- Polgar JM, Rudzicz F and Boger J. CARE-RATE: an online resource system for caregivers of persons with dementia. In: *International Society for Gerontechnology*, Nice, France, 28–30 September 2016.
- 60. Boger J, Rudzicz F, Chinaei H, et al. Care-rate: initial development of an artificially intelligent online tool for connecting caregivers to relevant support. In: *Rehabilitation Engineering and Assistive Technology Society of North America*, New Orleans, LA, 28–30 June 2017.
- Duggleby W, Ploeg J, McAiney C, et al. Web-based intervention for family carers of persons with dementia and multiple chronic conditions (my tools 4 care): pragmatic randomized controlled trial. *J Med Internet Res* 2018; 20: e10484.
- 62. Gaugler JE, Hobday JV, Robbins JC, et al. CARES[®] dementia care for familiesTM: effects of online, psycho-educational training on knowledge of person-centered care and satisfaction. *J Gerontol Nurs* 2015; 41: 18–24.
- Fischer SH, David D, Crotty BH, et al. Acceptance and use of health information technology by communitydwelling elders. *Int J Med Inform* 2014; 83: 624–635.

- Nielsen J. 10 heuristics for user interface design. Nielsen Norman Group, www.nngroup.com/articles/ten-usabili ty-heuristics (1995, accessed 7 April 2018).
- 65. Johnson J and Finn K. *Designing user interfaces for an aging population: towards universal design*. Cambridge: Morgan Kaufmann, 2017.
- Bouma HH, Legein C, Melotte HE, et al. Is large print easy to read?: Oral reading rate and word recognition of elderly subjects. IPO Annual Progress Report, Report no. 17, 1982.
- 67. Morris JM. User interface design for older adults. Interact Comput 1994; 6: 373–393.
- Bornstein S. 8 Principles for Elderly User Experience Design. *Pumika Blog*, https://blog.pumika.com/2016/07/ senior_ux_8_principles (2014, accessed 4 November 2017).
- 69. Shaikh DA and Lenz K. Where's the search? Reexamining user expectations of web objects. Usability News, http://usabilitynews.org/wheres-the-search-reexamining-user-expectations-of-web-object (2006, accessed 4 November 2017).
- Sherwin K. Placeholders in form fields are harmful. Nielsen Norman Group, www.nngroup.com/articles/ form-design-placeholders (2014, accessed 10 November 2018).
- Bowe F. Why seniors don't use technology. *MITS Technol Rev* 1998; 91: 34–40.
- Nielsen J. Change the color of visited links. Nielsen Norman Group, www.nngroup.com/articles/change-thecolor-of-visited-links (2004, accessed 4 November 2017).
- 73. Murch GM. Physiological principles for the effective use of color. *IEEE Comput Grap Appl* 1984; 4: 48–55.
- 74. Kurniawan S and Zaphiris P. Research-derived web design guidelines for older people. In: *Proceedings of the 7th International ACM SIGACCESS conference on*

computers and accessibility, ASSETS '05, Baltimore, MD, 9–12 October 2005. pp.129–135.

- 75. National Institute on Aging. Making your website senior friendly: tips from the national institute on aging and the national library of medicine, http://www.lgma.ca/assets/ Programs~and~Events/Clerks~Forum/2013~Clerks~ Forum/COMMUNICATIONS-Making-Your-Website-Senior-Friendly–Tip-Sheet.pdf (2009, accessed 4 November 2017).
- McGrew J. Shortening the human computer interface design cycle: a parallel design process based on the genetic algorithm. *Proc Human Factors Ergonomics Society* 45th Annual Meeting 2001; 45: 603–606.
- Ovaska S and Raiha KJ. Parallel design in the classroom. In: *Proceedings of CHI'95*, Denver Colorado USA, 1995, pp.264–265.
- Nielsen J. Usability engineering. Boston: Academic Press, 1993.
- Adams S and Berg M. The nature of the net: constructing reliability of health information on the web. *Info Technol People* 2004; 17: 150–170.
- Adams S, de Bont A and Berg M. Looking for answers, constructing reliability: an exploration into how Dutch patients check web-based medical information. *Int J Med Inform* 2006; 75: 66–72.
- Adams SA. Revisiting the online health information reliability debate in the wake of "web 2.0": an interdisciplinary literature and website review. *Int J Med Inform* 2010; 79: 391–400.
- Adams S. Post-panoptic surveillance through healthcare rating sites: who's watching whom? *Inf Commun Soc* 2013; 16: 215–235.
- 83. Davis B, Nies M, Shehab M, et al. Developing a pilot e-mobile app for dementia caregiver support: lessons learned. *Online J Nurs Inform* 2014; 18: 21–28.