Barriers to Online Dementia Information and Mitigation

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ABSTRACT

There is growing interest in HCI to study ways to support access to accurate, accessible, relevant online health information for different populations. Yet, there remains a need to understand the barriers that are posed by the way our platforms are designed as well as how we might overcome these barriers for people with dementia. To address this, we conducted sixteen interviews and observation sessions with people with mild to moderate dementia. Our analysis uncovered four barriers to online health information and corresponding mitigation strategies that participants employed. We discuss how HCI researchers may apply these findings towards new technical approaches and standards concerning information accessibility and credibility for neurodiverse populations. Finally, we broaden the scope of HCI research to include investigations of the accessibility and credibility of online information for people with age-related cognitive impairment independent of proxies.

CCS CONCEPTS

• **Human-centered computing** → Accessibility; Accessibility theory, concepts and paradigms; • **Security and privacy** → Human and societal aspects of security and privacy; Social aspects of security and privacy.

KEYWORDS

Dementia, Online Health Information, Cognitive Accessibility, Scams, Misleading Information

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1 INTRODUCTION

Accessibility is a critical focus for research in Human Computer Interaction (HCI) [50], and there is a growing interest in cognitive accessibility. Researchers are designing technologies to be accessible for individuals with intellectual or developmental disabilities, for purposes such as recognizing and reporting abuse [37, 101]; augmentative and alternative communication [26]; and independent travel [47]. Researchers are also investigating ways to improve the online information search strategies [7, 38, 65, 77, 84, 85, 103], data accessibility [107], and online cybersecurity [54, 55] for people with a variety of cognitive disabilities.

HCI researchers have studied ways to support access to accurate, accessible, relevant online health information for many different populations (e.g., transgender people [4], older adults [109], individuals with intellectual impairments [7], and blind or low-vision users [88, 102]). This research notes the ways that while key, health information can be difficult to access for groups facing discrimination, disability, or age-related changes. One population in need of better access to health information are people with dementia. Though there are many ways that people with dementia can take engaged approaches to managing their health and wellbeing, dementia is often framed in biomedical and social settings as a hopeless condition [3]. Dementia activist Kate Swaffer described "prescribed dis-engagement" – whereupon diagnosis, rather than providing resources to help newly diagnosed people manage their condition, physicians tell them to "go home and give up their pre-diagnosed lives" [90]. A lack of access to information appears to continue from this point, with informal caregivers often searching for health information on behalf of the person with dementia [3, 23, 87, 104].

The transfer of control over their health management can be disempowering and demeaning [96]. And, when people with dementia are not afforded access to health information on how to live well with their condition, there may be material consequences, such as the loss of ability to take an active role in their healthcare decision making [6, 64, 96] or loss of employment when people might otherwise be able to work with accommodations [13, 22, 83]. Though some past research has depicted those living with dementia as uninterested or unable to search for online health information [21, 23], researchers in HCI have demonstrated how people with dementia use Twitter [91], online forums [42, 43], and dementia specific websites [49] to seek and share personal experiences, resources, and medical information concerning dementia. However, we rarely look closer to the specific barriers that are posed by the

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way our platforms are designed or how we might overcome these barriers.

In this work, we took an action research approach to conduct qualitative observations and interviews with sixteen people with mild to moderate dementia. Our analysis uncovered the barriers that participants reported encountering with online health information due to 1) the lack of health information relevant to people with dementia (rather than caregivers or clinicians) concerning their specific type of dementia and decade in life; 2) information formats that were emotionally, cognitively, and sensorially inaccessible; 3) inaccurate and oversimplified health information; as well as 4) information which elicited distrust due to web-page design and perceived hidden agendas. We also describe the mitigation strategies people with dementia employed when they encountered each of these barriers, including strategies such as: making due with available information; reducing exposure to certain types of information; searching for alternative formats; considering the source of the information; acting as an information mediary; and collaboratively scrutinizing information.

These empirical findings are important for two reasons. First, it is necessary to understand the barriers people are facing – and the solutions that they have successfully employed – in order to create approaches for others who can benefit from seeking health information online. This can support cognitive accessibility researchers in designing future technical interventions to make online health information more accessible to neurodiverse populations. Second, our findings demonstrate that people with dementia are individually (and collaboratively) using online health information resources, and demonstrating ingenuity in navigating the barriers they face. This finding broadens the scope for HCI researchers from a focus on dyads or caregivers [7, 52–55], to considering the accessibility and credibility of online information from the perspective of individuals with age-related cognitive impairment.

2 RELATED WORK

Below, we describe past research concerning social media resources and online platforms for dementia-related information, and the limited research on barriers to online information for people with dementia.

2.1 Social Media Resources and Online Platforms for Dementia Information

Researchers have studied the use of existing social media platforms to disseminate dementia-related information, including testimonial videos, public service announcements, presentations, and interviews [48, 81, 82, 105, 110, 111]. Tang, Olscamp, Choi, and Friedman found testimonial videos of people living with Alzheimer's disease and their families were the most viewed type of dementia-related material on YouTube [92]. Researchers have theorized that YouTube is used as a resource to find dementia information because it provides anonymity in finding information for an often culturally stigmatizing condition [48, 111]. One project capitalizes on video as a beneficial medium by working with people with dementia to create engaging videos to promote early diagnosis for future viewers with dementia [5]. Others have studied online platforms [49, 91, 94] and forums [42, 43] for the dissemination of self-narratives of life with dementia. Twitter has been shown to act as a digital diary, not only to share what's happening in the daily lives of people with dementia, but also to "preserve the activities and memory" of people with dementia [94].

Researchers have also studied the sense of community and social connection in online communities. Twitter was found to be a place to find and connect with others living with dementia through sharing personal experiences [91, 94]. Craig and Strivens studied a Facebook group for those with younger-onset dementia, finding that the members of the online group were able to form a community of support with others living with dementia [16]. Within this online group, people with dementia are treated as the experts on dementia information [16], which is counter to the predominant deficit narrative surrounding the abilities of people with dementia [74, 108]. Online forums designed for use by people with dementia have also been analyzed for the community and social connections they provide [42, 43, 78].

In addition to social connections, online communities are also a place where people with dementia provide and receive dementia-related information. Some people with dementia engage in online forums to look for medical knowledge, exchange and piece together dementia-related information [42]. Below we describe the limited past research which alludes to the various barriers to online information for people with dementia.

2.2 Barriers to Online Dementia Information for People with Dementia

Although there is a lack of research directly studying the topic, recent studies allude to barriers that people with dementia experience in accessing and using information about dementia. These barriers include: difficulty finding relevant information [32, 44], interpreting information the way it is presented [19, 24, 43], and vulnerability to misinformation and scams [20, 43].

Past work has shown people with dementia have unique sensory and cognitive accessibility needs that must be accommodated to make online information accessible [19, 24, 49]. Examples include difficulty reading text-based information due to excessive character count, color contrast, and multiple choices displayed on a webpage causing visual overstimulation [19, 24, 49]. In terms of cognitive accessibility, research analyzing the content on an online forum targeted for use by people with dementia found that users intentionally provided information to others with dementia in digestible formats [43], yet barriers due to visual overstimulation with numerous posts still exist [19]. In this paper, we reveal accessibility considerations that people with dementia report, when encountering online health content.

In addition, exploitative dementia-related content online persists [20, 43], and is shared along with other misinformation in online forums for people with dementia [43]. Dixon and Lazar found some people with dementia avoided searching for dementia-related information online due to encountering health misinformation [20]. Our work uncovers credibility barriers and mitigation strategies participants with dementia utilized when they encountered online health misinformation.

3 METHOD

We conducted an analysis of data from a larger research project to investigate the health information behaviors of people with dementia. In both data collection and analysis, we employed an "action research" approach [33] to actively include two people living with dementia. These two researchers served as "dementia experts" on our research team to better communicate with and gain a more in-depth understanding of the study participants. They completed ethics board training and participated equally to help conceptualize the study, gather and interpret data, and document the findings [33]. Below, we describe the procedures we used for this study, participant details, and our analysis method.

3.1 Procedures

Participants with dementia were recruited through our networks, which include members of peer support groups and large dementia advocacy organizations, and snow-ball sampling. To qualify, participants had to self-report a diagnosis of mild to moderate dementia, and had to have looked for dementia information online.

Consent forms were emailed to participants three days before their scheduled session, and participants could ask researchers questions about the study and form prior to verbally consenting to participation. Aligning with best practices when working with people with mild to moderate dementia [34], we assumed participants' capacity to consent [93]. While reviewing the verbal consent form together, we were attentive to participants' possible lack of capacity to consent. As a precaution, we were prepared to use the University of California Davis protocol to determine capacity [97] in the instance a participant possibly lacked capacity to consent. However, this was not used, as all participants demonstrated the capacity to consent verbally.

After each participant gave verbal consent, a short demographics survey was completed. We then followed a contextual inquiry technique [45] which consisted of two parts: a semi-structured interview (about 40 minutes) followed by a 20-minute observation session. We choose this approach because it provides the opportunity for participants to verbally express their thoughts and experiences but does not limit our data solely to recall and verbal descriptions, which can be difficult for people with dementia.

For the interview portion, we asked questions, such as "How do you obtain dementia related information?"; "Are you satisfied with your process for finding dementia related information?"; and "How would you improve your process of obtaining dementia information?" Additional questions explored topics guided by the informants themselves. We benefited from the action research approach of involving target community members, as dementia experts drew on their wealth of knowledge to inform interview discussions. For example, the academic researchers were not aware of specific therapies and supplements for dementia whose validity are disputed, such as the Bredesen protocol [61], which dementia experts brought up during interviews to initiate conversation on determining the reliability of dementia information. Though we included some questions explicitly asking about technical mediums to obtain information (e.g., "What technologies are you using, if any, to find information concerning dementia?") all participants reported using technology-based mediums to obtain information, though they also consulted other sources. Thus, the focus of this work centered on online information.

For the observation session, we provided participants with eight problem scenarios from which to choose and asked them to walk us through their search strategies. Our team collaboratively created these scenarios based on related work and our past experiences living as or working with people with dementia. During the observations, once a participant chose a scenario and began to demonstrate their search process, we asked questions to help participants reveal their thought processes. Examples of questions include: "Why did you choose this site?"; "How do you decide if information is trustworthy or not?"; "How do you feel about the way this information is presented?" We avoided situations where individuals might show us personal account information. In instances when participants navigated to an online resource that was not accessible (e.g., a journal article with too much medical jargon), after discussing the inaccessibility of the resource, participants were asked to continue searching for other resources to address the problem scenario.

After each study session, participants received a $20 Amazon gift card as compensation. The study took place in August and September 2020 using Zoom video-conferencing due to the Covid-19 pandemic. Each interview and observation session was audio/video recorded, resulting in over fifteen hours of data. For all sessions, two team members were present. The first four sessions included two academic researchers, one leading the session and one taking observation notes. For the remaining twelve sessions, one dementia expert led the session while one academic researcher observed. Dementia experts led six sessions each with those participants that they recruited. All procedures were approved by our University Institutional Review Board.

3.2 Participants

Sixteen people with mild to moderate dementia participated in this study. The average age of participants was 66 years old (range 57-79). When asked "what is your gender?" with a fill in the blank survey, eight participants identified as female and eight as male. Fifteen identified ethnically as Caucasian and one, Kevin, as Asian. Participants reported their residence in either the US, UK, Canada, or Australia. All were "retired" or "retired on disability;" Donna specified her employment status as "volunteer" though most participants were also active volunteer dementia advocates and/or participated in peer-support groups. See Table 1 for further participant demographic information.

3.3 Analysis

Audio recordings of each session were transcribed using Otter.ai, then verified by academic researchers. Consistent with the constructivist grounded theory approach [14], we first open coded transcriptions. Through team discussions of codes such as "online information gathering strategies," we collaboratively identified emergent themes, such as "barriers to information sources," and "barriers to technological resources." The first author then merged all codes into themes, resulting in an initial codebook. The dementia experts edited the codebook for further clarity of code names and definitions. Another round of team discussions was held to collaboratively refine the codebook. For example, the codes, "barriers to

Table 1: Participant Demographics

Pseudonym	Age	Gender	Type of Dementia	Education	Technical Confidence
ArNold	68	Male	Vascular dementia	Some college, no degree	Somewhat confident
Dawson	73	Male	Early Onset Alzheimer's	Some college, no degree	Somewhat confident
Lucy	67	Female	Early Onset Alzheimer's	Bachelor's degree	Very confident
Carter	61	Male	Vascular dementia	Some college, no degree	Very confident
Michael	61	Male	Functional Neurological Disorder	Some college, no degree	Somewhat confident
Sadie	79	Female	Alzheimer's Disease	High School Diploma	Somewhat confident
Lila	Range (60-70)	Female	Early Onset Alzheimer's Disease with a Lewy Body Component	Multiple Bachelor's degrees	Very confident
Carly	62	Female	Frontotemporal dementia	Master's degree	Somewhat confident
Gale	71	Female	Frontotemporal dementia	Master's degree	Somewhat confident
Eva	57	Female	Lewy-Body dementia with Behavioral Disturbances	Bachelor's degree	Somewhat confident
Levy	61	Male	Lewy-Body dementia/ Parkinson's	Some college, no degree	Only a little confident
Velma	61	Female	Vascular Dementia	Bachelor's degree	Somewhat confident
Thomas	68	Male	Variant of Alzheimer's slow moving	High School Diploma	Not at all confident
Kevin	79	Male	Frontotemporal dementia	Master's degree	Somewhat confident
Toby	61	Male	Early Onset Alzheimer's and Lewy Body	Master's degree	Somewhat confident
Donna	62	Female	Semantic Variant of Primary Progressive Aphasia	Master's degree	Somewhat confident

information sources" and "barriers to technological resources" were grouped under the clearer, overarching code, "barriers to gathering and accessing information." This version of the codebook was then used during the process of focused coding.

Each transcript was focus-coded twice, once by a dementia expert and once by an academic researcher, to ensure we understood participants' intended meaning and account for a tendency of the academic researchers to miss nuances that the dementia experts noted. We followed an iterative process of engaging with the data, comparing codes, performing pattern recognition, and memoing over several months, with weekly team meetings to discuss these memos and connections between codes. During this process we checked tentative themes against transcripts and even returned back to the original videos to confirm major themes. Aligning with typical outcomes of grounded theory analysis [95], the results of our analysis provide greater conceptual clarity through a full explanation of the barriers to online health information people with dementia experience.

3.4 Limitations

Out of sixteen participants, fifteen identified as Caucasian and one as Asian, creating a dominantly white racial group. More research is needed to better understand the diverse racial, linguistic, socioeconomic, cultural and age differences in this population (especially given the prevalence of dementia in African American and LatinX communities [2]). There is an opportunity to collaborate with researchers and organizations such as Black Dementia Minds [59] to address the overrepresentation of white individuals in our research.

With the average age of participants just 66 years old, we also acknowledge that our study over represents people with younger-onset dementia (diagnosed under the age of 65 [1] representing only 9% of global diagnoses [106]). Recruiting this relatively-younger group of participants may have resulted from the hesitance of the older generation to self-identify as a person living with dementia, due to long-held stigma [6, 90] and misinformation about dementia that can lead to an unwillingness to discuss personal experiences with researchers [86]. More likely, the overrepresentation of younger people with dementia was due to the fact that they had been active in peer support groups or as dementia advocates, which also made them more willing to and interested in helping researchers gather information related to dementia.

Finally, most participants in this study self-reported as somewhat or very confident using technology, which may not be representative of the general (and older) population with mild to moderate dementia. However, research reveals a trend towards greater technology use by individuals with dementia, with more than 50% of people with mild cognitive impairment or dementia using smartphones and tablets almost every day [28].

4 FINDINGS

Our analysis revealed four barriers that obstructed participants from accessing online dementia-related content: information which lacked relevancy, was inaccessible information, inaccurate and oversimplified, and elicited distrust. Below we elaborate on each of these barriers and describe participants' mitigation strategies for each.

4.1 A Lack of Relevant Information

Participants described the lack of relevant dementia-related information targeted to an audience of people with different types of dementia. And, an unequal amount of information about the many different kinds of dementia (with over 100 known) made it harder for someone without a medical background to understand their diagnoses. Michael, first diagnosed with Lewy body dementia and later with a rarer dementia, had considerable trouble finding anything about his new disease: "You know this 'functional neurological disorder' doesn't seem to be as well-known as Lewy body. And definitely not as well-known as Alzheimer's. Alzheimer's has a plethora of stuff on it; Lewy body: there's a good amount. This stuff [functional neurological disorder]- here, not so much."

Gale explained the need for information related to life stage, as people diagnosed at a younger age may "have their job taken away, they don't have income, and they can't pay mortgage. They have dependents, like children, school-age" and therefore, need information for social services. By contrast, Sadie wanted information about living with dementia for more than two decades, as she had. In her observation session, she conducted a Google search for "alzheimer's at 26 years after diagnosis becoming unlike myself." She explained her personal concern about "some kind of nasty part of myself coming out when I get angry. And I don't know how to control it or what to do." Sadie was disappointed with links on the first page of search results: "This is very common. You can't find out because they just don't think you're still able to talk when you had it 26 years."

Several participants remarked that informational resources were mainly directed at caregivers or medical professionals, making the task of finding relevant information much more difficult. For example, while reviewing a large dementia advocacy organization's website, Velma observed "there's a lot of stuff about caregivers. And I will be wondering, well what about me?" Michael noted that information can be targeted at medical practitioners. He described how a large dementia advocacy organization hosted a talk from a medical doctor, specializing in Lewy body dementia, who spent the majority of the talk introducing himself and his credentials. Michael believed this talk would provide him as someone living with Lewy body dementia with crucial information, but found it oriented more towards medical professionals.

Making Do with the Available Information: Because of the lack of relevant information, some participants found ways to make do with the information that was available. Kevin demonstrated how he interprets information written for caregivers to make it applicable to his own situation when he selected the article "Handling Dementia and Anger, How to Respond to Anger and Aggression" published by a large Alzheimer's organization. Kevin noted the article's main focus was to provide "tips for coping" to caregivers. But, the article also included "six common causes of aggression." Kevin learned about factors such as "poor food intake, misunderstandings, distortions of reality, paranoia" and applied them to his own life to see if he was experiencing these things. He then used these findings to help him "phrase it [his next search] in the way that I want to phrase it" to learn more. Sadie also identified a resource that described "the five things you should do when you're a caregiver." The article explained some of the symptoms of dementia and how to care for someone experiencing those symptoms. Sadie described how, "Even though I am forgetting and even though I'm going downhill, I think this [article] has portions of my life that I would like to put into [practice]." She saw the relationship between someone living with dementia and an informal caregiver as: a two-way street, and in reading tips to stop an argument, Sadie remarked "I can stop an argument just as fast as he [husband] can, by just walking away. And so I think it's good lessons for both." Individuals adapted to the preponderance of resources for caregivers by sifting through information and interpreting it in a way that was relevant to them.

4.2 Inaccessible Dementia Information

Participants described encountering barriers due to the inaccessibility of dementia-related information.

4.2.1 Emotional Inaccessibility.

Participants described how much dementia information is emotionally inaccessible, in part due to being overly pessimistic. Lucy described how "if you just type it to say 'dementia', You'd come up with loads and loads and loads of negatives" on various dementia related websites. Thomas believes this negative information "starts with the word 'dementia'. . . which has, in its root, the word 'demented'... And it's a negative, it's pejorative." Such labeling "connotates, in a lot of people's brains, things like sexual perversion, and drooling all over yourself, and just unable to do this, that or the other thing, and I mean, the whole spectrum of these very negative things."

As others described, overly pessimistic dementia-related information can have serious negative impacts on the mental health of people with dementia. Velma described existing resources as "very depressing. . . there's nobody's giving you any hope. It's just like, 'well, the outcome isn't good."' What was particularly depressing to Thomas was finding "so much written about, well, you know, you have this kind of life expectancy probably or this or that. And, you know, you need to make plans for a rest home and... get your ducks in a row," referring to making end of life preparations. In addition to life expectancy, Dawson detailed how information on theories of why individuals develop dementia, medication side effects, and medications that treat the "symptoms and not the disease" are equally harmful for his mental health: "I can get depressed over it, I can get anxious about it."

Reducing Exposure: One mitigation strategy participants took was to reduce exposure to overly pessimistic information. For example, when Eva received dementia-related organizations' newsletters in her email, she "delete[s] the news," meaning the whole newsletter, because "I don't want to have to deal." Donna "never go[es] to" resources by a certain dementia advocacy organization because "they're too negative." Some people avoided particular kinds of information: Lila never looked up information concerning stages of dementia, because "Why add something else on my plate that could potentially make me more anxious?" Instead of regulating what sources of information he used, Dawson regulated the amount of exposure he had to dementia information: "I try to pace myself with it... over a period of time. . . I'll just say 'Ok, I've had enough for today'."

4.2.2 Cognitive and Sensory Inaccessibility. Participants described cognitive and sensory barriers posed by inaccessible dementia information. Text length was one major barrier. Levy explained, "if [written information] starts getting too wordy, I can't pay attention to it." Participants wanted abbreviated versions, providing "information that's fairly clear and concise," ideally in "larger font and shorter bullets" [Levy] with a "maximum usually. . . about four pages. . . well-presented, well-written, non-technical... readable" [Carter]. Participants referred to the Dementia Engagement and Empowerment Program [39] newsletters as an example of limited word count providing clear information.

In addition to word count, participants noted other ways text-based content could be "hard to decipher" [Velma]. This was especially apparent during the observation session when participants encountered medical terminology in research papers and other resource. As Carter explained about a research article published by the US National Institute of Health, "'I know it's going to be quite complicated. . . because it's a government document." Carter explained that the medical terminology and jargon was "way beyond my comprehension," and that "even if you've got a scientific mind. . . it can be difficult to interpret." To make medical research papers more accessible, Carter suggested that researchers provide one page, bulleted summaries of research findings. Having the text written by a person with dementia made it more accessible for Sadie, who explained her approval of a blog webpage written by someone with dementia after scanning several dementia advocacy organization websites. She noted, "that's not coming from my caregiver, it's coming from the person with dementia, so I can really understand it." The blog article featured a series of short paragraphs entries by date that accounted for the author's reflections on "living with dementia in the United States during the pandemic."

Sensory changes also contributed to text-based content being inaccessible. Participants described dementia-related changes in their visual abilities which affected their ability to read: "through dementia - I have a visual impairment. And that is, I don't read ordinary script anymore, because it makes me have, like, a motion sickness. It has to be in a certain font... and spaces in between... it's a certain way of me reading" [Lucy]. Arnold described the compounding interaction of changes in visual ability and changes in his reading comprehension ability: "I can't read cuz I don't understand what the words mean. And I have trouble following; like I'll go to the end of the sentence and then, to start the next one, I have trouble locating it." Arnold elaborated, "It's not that I'm not interested... I'll find something, and then I'll have trouble understanding... what the words - what they're saying... And then like, I'll go back five or six times. And I might get to word - the meaning of one word."

Searching for Alternative Formats: Participants mitigated these challenges by "gather[ing] the information, and read[ing] it and process[ing] it" [Lila], in a format that was accessible to them. For some participants, that was through online videos or lectures. For others, in-person verbal explanations, or text-based information were preferred. Carter quoted dementia rights advocate, Richard Taylor, who had described how each person living with dementia has "to start finding your own route to discovering the information that is relevant to you. Because 'If you've met one person with dementia, you've met one person with dementia'." He elaborated, "Everybody's different, everybody's got different characteristics, everybody's got certain difficulties, and no two people are alike." Though there were themes in what content was perceived as accessible or inaccessible, each participant had to find the mode of accessing information that was best for their unique and changing abilities.

Some participants preferred text-based information, such as Toby, whose "preferred form of learning is to read something from a trusted source," though he noted he also "get[s] a lot [of information] verbally." Donna explained settings where receiving important information verbally was challenging: "in a short [doctor's] visit, especially if I've got some new thing [potential symptoms] going on, I might be stressed, so... my ability to understand what he's saying is how I found auditory understanding quite difficult." Donna preferred to read written information because, "I can take my time. I look words up... that I can't remember what they mean."

Other participants described looking for informational videos as alternatives to written or verbal information due to difficulty with medical jargon and reading comprehension. As Gale explained: "when I was told [by her doctor] FTD [frontotemporal dementia], I just Googled frontotemporal dementia... and gradually worked through a lot of entries under it until I actually found something that made more sense to me" which was "a doctor's lecture to medical students. . . that really explained the different types of frontotemporal dementia." Gale explained that this video was understandable because it used "clear English - plain English."

For one participant, Arnold, online information wasn't accessible, so he had to receive information in-person. He described how, "Navigating the internet was very frustrating. Not frustrating - aggravating. I threw a cup of coffee at my computer screen!" Reading comprehension was challenging: "I don't understand what the words mean. And I have trouble following, like I'll go to the end of the sentence and then to start the next one." He tried auditory online methods such as podcasts but these were inaccessible because, "I can't figure out how to do it." Because different online formats were inaccessible, Arnold resorted to having "lots of conversations with social workers there, built up a great relationship with a couple of them, also with the communications director." These relationships provided him with the "information I've acquired, like medications, who to talk to" [Arnold]. Although he preferred these verbal interactions for information seeking over searching for information online he noted, "Even when I hear, sometimes the words are hard to understand. So, it's all frustration" [Arnold].

4.3 Inaccurate and Oversimplified Dementia-Related Information

Participants described barriers due to encountering inaccurate and oversimplified dementia-related information online.

4.3.1 Inaccurate Information. Lila described how "once you get the diagnosis, you run; you read things online, and they're not always accurate." She referred to "doing a generalized search and getting millions of different things pop up" which made it difficult to determine which of those resources are accurate. Donna also raised concerns for evidence-based research, due to the fact that it may be outdated: "I'm doubtful of lots of research, even my own [research findings] because you know a piece of research comes out and everyone is excited... and then in five years' time, new researchers prove that that research – it's not quite right or is completely wrong. So, I'm really open to the fact that everything I believe today might be proven to be wrong tomorrow."

Two participants described how relying on others for anecdotal information is not consistently reliable, as subjective and medically-inaccurate information may be shared. Donna believed support groups "give out way too much medical advice," which can be "really dangerous." Though it was against the organizational guidelines of the support group "even if we're a past healthcare professional," some members still shared this kind of information. Thomas echoed this concern, noting: "facts drawn from experience don't necessarily make them facts." Thomas recognized the risk of impaired judgment affecting both his perception of the reliability of their information and the accuracy of others with dementia reporting it: "they're all just as dementia-related as I am."

Considering the Source of the Information: Participants verified a source by looking into "who's written it" [Carly], author credentials [Kevin, Toby], and the authors' other work [Lucy]. Lila had "to redefine how I did my searches so I would get more accurate information," referencing the need to find current research. In addition to identifying outdated information based on publication date, participants compared new information to what they knew about dementia based on research or their own experience, such as with information about how people with dementia "can't make decisions for themselves" [Lila] and "have a 3-8 year timeframe [life expectancy] after diagnosis" [Velma]. Velma argued that such research was on "later stages that people were being diagnosed. . . I'm sure that's based on 20+ years-ago information." These information sources were perceived as providing misleading dementia information, and were avoided.

Referring to Academic or Clinical Research: Several participants described validating the accuracy of dementia-related sources by looking into academic or clinical research papers. For example, Donna describes how, "I don't go to Google; almost all I go through my university and get, you know, proper, evidence-based research." Others used sites like WebMD and the Mayo Clinic because, when they read information from those resources, they looked into the references that were cited [Kevin, Toby, Carly]. As Toby described when he "double check[ed]" the information a resource provided against the academic sources referenced, "very seldom is there any significant difference if you're using these credible sites." Notably, participants believed that referring only to academic or clinical research papers may not reflect "your average person living with dementia" [Lila], realizing that the general public may not have easy access to university or medical research articles.

Ensuring the Voices of People with Dementia are Included: One mitigation strategy to ensure the validity of information was to check whether it included the voices of people with dementia. Michael described his trust in information from authors living with dementia who shared "real testimonials" online, as long as "somebody leaves her name first, or first and last, they're putting their reputation on the line." He gave an example of a testimonial: "'I went to this branch - that Cleveland Clinic - and they were excellent and this is my doctor'." These types of testimonials "make the site something that you feel you can trust that the information is accurate" [Michael].

Others reflected on "whether I think it's been gathered correctly" [Carly], which included whether individuals with dementia was included in the research process. One participant, Lila, wanted to make sure that people with dementia were a part of the research team: "a lot of research is done about dementia. And it doesn't involve the person living with the disease process. . . And I think to get accurate information, the voice has to be included." She elaborated that "it's difficult" to determine whether researchers have adequately involved people with dementia in projects because, "researchers will get people to sign on with dementia, but they don't adequately use them. They use them to get the money, but at the table, they are not seen or heard."

4.3.2 Oversimplified Information. Some participants described how large dementia advocacy organizations can oversimplify content, providing inaccurate and even misleading dementia information. Lucy noted, while browsing a large dementia advocacy website, that it provided oversimplified causes of dementia, perceiving the message of the source as: "well, if you'd looked after yourself [your health], you may not have got Alzheimer's? (scoffs)." For example, the website stated, "There is a link between head injury and future risk of dementia," and as a preventative measure, one should, "protect your brain by buckling your seatbelt." To which she responded "Really? (laughs) It's so simple isn't it... I've always used a seatbelt. Still got Alzheimer's." Lucy described how more accurate information would include "the real nitty-gritties of the clinical" reasons why people develop dementia, such as "plaques and tangles" in the brain, or because "it's hereditary; it's genetic." Lila described friends who, "read that we have two to five years [life expectancy] and that it's going to be a downhill slant [progressive loss of abilities]" and then experienced declining physical health through self-fulling prophecy. Lucy described such oversimplified information as "soul-destroying," with potentially life-threatening consequences.

Acting as an Information Mediary: To mitigate the effects of information oversimplification, participants acted as or appreciated others who served as information mediaries, meaning they took information and passed it to others while adding additional context. Lucy described how she acted as an information mediator for members of the nine support groups she attended by sharing information with new members. For example, she acknowledged the probable accuracy of information on your average lifespan but added nuance and complexity in that, "we're all individuals, so some, unfortunately, yes, they have died within that span. Some of us don't; we go on! We go on for years." In this way, information mediaries provided a crucial asterisk to the oversimplification of the realities of individuals living with dementia, adding information to provide a more complete, nuanced understanding. Lila described the importance of these information mediaries: "it wasn't until we got together with others [with dementia] or found better information that we started to actually improve."

4.4 Information Which Elicits Distrust

Participants described encountering information which elicited distrust due to potential conflict of interest, exploitation, and false claims of cures. In some instances, participants described click-bait that attempted to sell teas, herbs, and oils with the promise that "Your brain is going to clear up" [Thomas]. Lucy recognized that such sales pitches were not random: "scammers are out there [on the internet] and find out you are a person with dementia; they will try and email you and say 'oh, we just got an amazing discovery - it's this pill you take and your memory will come back'." Carter pointed out that "people [with dementia] are likely to be victims of scams" due to their changing "capacity to understand" and determine what is exploitative. He explained that people with dementia have "got to be really, really careful" and develop mitigation strategies while they still have capacity.

Participants also described exploitation as any online content with "another agenda" [Michael], meaning the primary goal of the resource was not to provide information to help readers with dementia. Michael described going to nationally recognized dementia research clinic websites for further information on Lewy body dementia, only to be asked to "answer 10 questions first about your blood pressure, your weight, your blood sugar." Such data mining may not be intended to harm the reader, as clinics may be looking to recruit clinical trial participants. However, Michael stated that "trust goes out the window then, because they have another agenda." Other aspects of websites which elicited distrust included pop-ups which asked for a financial commitment such as signing up "for subscriptions" and often having to add "bank details" [Carter]. Michael recognized targeted advertisements based on data mining, which he both distrusted and resented. After searching online for "Lewy body dementia. . . the next thing you know, you got five people or five different ads for life insurance!"

Some participants even expressed caution about information sources that were generally trusted, such as well-known medical institutes and government health agencies. The concern here was about conflict of interest from funding streams that might lead organizations to publish misleading or inaccurate information. For instance, Donna has seen organizations "promote... a cure type drug" and "then a month later, we'll find out that we're not actually close to a drug for a cure." She attributed this to, "if you're getting a couple of hundred thousand dollars from a pharmaceutical company, and they asked you to promote a research paper they've just put out of a possible new cure. . . you kind of have to put it out." Toby also mentioned how funding priorities could affect the information that was shared by large Alzheimer's organizations, who may have a "vested interest in a certain message" to continue to receive donations and funding.

Avoiding Information Sources with Attributes that Elicit Distrust: Some participants sought to mitigate their risk of being scammed by avoiding sources with certain attributes. For example, participants described determining, over time, which organizations had a "vested interest" [Carter, Thomas] in publishing dementia-related information. Carter avoided, "anything's that got '.gov' in it" due to a perception that government sources were shaped by the "standpoint" of the political party in power. Carly critically reflected on "who's the source" of the information, and Levy "stay[s] away" from all news programs because they "haven't proved reliable."

On web pages that requested personal data, Michael brought to a "halt any further investigating on that site." Toby distrusted ads at the bottom of the page, so he avoided scrolling down too far any page, "because that's where ads usually start." However, his strategy sometimes thwarted his ability to find useful information. During his observation session, one website had a link to "diagnosis and treatment" at the very bottom of the webpage, and when the researcher pointed out that the information he sought was on the page, Toby stated, "the way they set it up. . . I've stopped reading because that's where ads usually start."

Collaborative Scrutinizing Information in Online Dementia Communities: Participants used this mitigation strategy in response to two barriers: information which elicited distrust, but also inaccurate and oversimplified information. To verify the accuracy of information, participants described using platforms such as Twitter to "see what [comments] other people have left" about the author, "to make sure that person's legit" [Lucy]. In a similar way, Velma utilized support group Facebook pages to scrutinize information with peers. If she "find[s] something and think[s] I'm not so sure about it. . . I'll put it on to our [dementia advocacy Facebook group]. . . you're not the only one doing the research and it's sort of a shared experience."

To scrutinize the trustworthiness of a resource, product, or therapy, Carter curated his Twitter account to only follow others living with dementia and researchers, where "the vast majority of them I've met personally... through Zoom" and he can "vouch for people for their credibility. And their honesty... hold on a better word... and their capacity to understand [ability to make accurate judgements], cuz what one person considers to be exploitative may well be completely genuine." He used this account to check the validity of certain therapies and drugs, where "people will share [on Twitter] and say [to] be careful of this particular thing." Together, his community identified one form of exploitation: dementia aids, "clocks with bigger numbers. . . they're hugely exploitative because of the prices that they charge." So in a process of joint sense-making, the members made "suggestions. . . like you can get a similar clock from this organization for [only] 10 pounds."

5 DISCUSSION

Our analysis of sixteen contextual inquiry sessions with individuals with mild to moderate dementia detailed the barriers participants experienced in accessing online health information, as well as mitigation strategies they employed in face of these barriers. Below we return to findings around information accessibility and credibility and discuss how HCI researchers can apply these findings towards new technical approaches and standards.

5.1 Implications for Online Health Information Accessibility

Our findings indicate the inaccessibility of online health information for people with dementia. This is an important area for future work to consider, as access to health information is a basic human right [98], which when violated may lead to unnecessary health inequity [58]. Below we first situate the accessibility needs of people with dementia within the broader information accessibility needs of people with cognitive disabilities. We then detail the importance of emotional accessibility for participants in our study, discussing ways technology could be used to address the emotional inaccessibility of online health content. Finally, we discuss opportunities for dementia research in HCI to produce more accessible research outputs.

5.1.1 Situating Dementia within the Cognitive Accessibility Space. The information accessibility barriers of people with dementia in our study share commonalities with individuals with other cognitive impairments. For instance, participants described barriers similar to individuals with attention-deficit/hyperactivity disorder, who experience difficulty processing information with additional auditory noise [41, 56], as well as those with dyslexia who face inaccessibility due to certain fonts [76]. There are also overlaps of accessibility considerations with the autistic community, which we describe further in section 5.1.3.

Identifying commonalities such as those above opens opportunities to test technologies designed for individuals who share similar barriers. Examples of web-based systems designed for other communities that may help address information accessibility needs of people with dementia include the Easier system, which uses lexical simplification, synonyms, and definition generators [57]; browser extensions that remove visual clutter and advertisements from webpages [73]; and text-to-speech systems that convert online content [40].

Even with similarities to other cognitive disabilities, there are information accessibility needs unique to dementia. One example is the ways participants described interpreting content written for other to make it relevant to themselves. This mitigation strategy may become more difficult with the progression of the condition which introduces changes to abstraction abilities [35] and applying general information to individual contexts [32]. Web-based systems could be designed to address this barrier as well as health literacy concerns. As an example, a browser extension could interpret and highlight health information for different audiences (e.g., person living with dementia, caregiver, clinician). It is key to avoid oversimplifying in a patronizing manner, for example by having the reader indicate their level of comfort with the terminology associated with that resource and having a tool respond accordingly. Addressing barriers posed by the need for health literacy has a wide range of important applications, such as use of electronic health records and patient health portals.

5.1.2 Emotional Accessibility. Our findings respond to a call of past research to understand the intertwined nature of emotions and utilization of technology by people with dementia [51]. Encountering emotionally inaccessible information impacted participants' ability to approach and comprehend information as well as continue with their everyday lives. Participants described how interacting with overly pessimistic information online elicited anxiety and more severe mental health concerns, or could lead to a self-fulfilling prophecy involving the loss of abilities. Following the lead of participants who reduced or eliminated exposure to emotionally inaccessible information, in the remainder of this section, we identify opportunities to address the emotional inaccessibility of online health content.

First, there is potential in scalable approaches to assess the emotionally inaccessibility of information, given the many sectors that produce and disseminate information about dementia or information that people with dementia encounter. One approach could employ linguistic inquiry to analyze the tone of information [69]. Though sentiment analysis tools may be a helpful first step, it is not clear whether they could accurately determine the emotional impact of information given the specific ways these tools have been found to be biased (e.g., age-related bias [18]). For this reason, it is key to include people with the condition under study to assess emotional accessibility to help researchers understand the dimensions and impact of information content, form, and delivery method. Another approach could use affective computing systems [70] to learn what content is emotionally distressing as a way to adapt online health content to individual rather than general needs.

Though it is important to create more emotionally accessible information, there is important information that may be impossible to translate as positive. Thus, tone could be assessed to create automated content warnings for online health information (similar to work with social media posts [89]). Another, more individualized approach might use health-aware recommender systems [79], which recommend resources personalized to individuals' set specifications. In the context of our findings, individuals might benefit from filtering out articles that use certain terminology (e.g., "can't make decisions for themselves"; a specified life expectancy), were written more than a decade ago, or do (or do not) include scientific terminology and explanations.

5.1.3 Towards More Accessible Research Output. Participants described the necessity of reading academic research papers, as credible and relevant sources of information. They also described accessibility barriers experienced when reading academic research papers. With this understanding that people with dementia are accessing the content that is written about them, as researchers, we have the opportunity and responsibility to make our work accessible. Below, we describe three directions towards more accessible research output, each of which leverage existing practices in HCI research.

Some participants described the accessibility of videos over text-based online health information due to increasing difficulties with reading comprehension. Researchers can include short video recorded presentations of papers – as has become the norm for remote conferences due to travel restrictions because of COVID-19. Posting these videos so that they are publicly available (e.g., via YouTube) in addition to the ACM digital library will make them more easily findable through the online searching methods described in our study.

When considering emotional accessibility, following an action research approach led us to identify and address some emotionally inaccessible publication norms. This included ascribing the source of information barriers to the design of technology rather than participant characteristics, as well as using pseudonyms to avoid the dehumanization invoked with participant identification numbers. We join researchers attending to the importance of accurately and respectfully representing research participants' identities [46, 67, 80], noting the importance of participant identifiers, terminology, and tone in research with people with dementia.

Word count and page length posed barriers for some participants, who noted around four pages as the upper limit. Given that CHI accepted papers are typically 7000-9500 words [15], there are opportunities for HCI dementia researchers to create abbreviated versions of academic articles, potentially using AI text-based summarization (as in [12]) and following well-established plain language guidelines [100]. This opportunity aligns nicely with CSCW initiatives towards blog posts summarizing articles for public scholarship [27]. In doing so, it will be key to navigate the tension between accessible and overly simplified, patronizing language.

Though the recommendations above are compatible with existing HCI practices, we can further benefit by drawing on publishing practices with research with the autistic community. With barriers to written text, similar recommendations have included creating videos to communicate information [8], social accessibility guidelines to attend to community preference for language in research articles [75], and for text to be concise in order to reduce cognitive burden [68, 75]. This responsibility has been taken seriously by The Journal of Autism in Adulthood, which requires that submissions provide lay-person "community briefings" [63]. Given the range of populations with whom HCI researchers work (where one group's needs may contrast with others), there are many opportunities ahead to make output more accessible to those living with the condition under study.

5.2 Implications for Online Health Information Credibility

Our findings concerning the credibility of online health information have implications for individuals with age-related cognitive changes. Past work has noted that older adults prioritize information that is available over all other criteria for scrutinizing a source [66], increasing their susceptibility to misinformation. Similarly, research with people with mild cognitive impairments found they are especially susceptible to scams and exploitation online because of impaired judgment [29, 52, 71]. Interestingly, participants in our study were aware of their changing ability to identify health misinformation, and exercised increased caution towards online health information. This heightened awareness of susceptibility to misinformation led participants to develop mitigation strategies to verify the accuracy of health information they found online. Below we discuss how the credibility concerns participants raised, as well as the strategies they developed, lead to three ways technology could be used to better indicate the credibility of online information for people living with age-related cognitive changes.

5.2.1 Adding Context. Participants described oversimplified health information as a type of misinformation, where information may be supported with scientific evidence while simultaneously misleading readers due to the omission of important contextual information. These findings have implications for the summarization of health information and surface tensions with the role of others as information mediaries.

Previous work has proposed addressing inaccessible long-form content by providing information summaries [19]. In this study, many participants similarly referred to websites that summarized a series of research articles as accessible (e.g., Webmd, the Mayo Clinic). Though summarization may make online content more accessible, this approach may cause credibility concerns similar to those identified for health "information snippets," which are often viewed as a self-sufficient "mini-article" and therefore make it less likely readers will engage with the full article to check its credibility [72]. Some participants in our study viewed summarized health information not only as misleading, but also as accusatory (e.g., in describing preventative behaviors). To combat this barrier, participants in our study wanted more context around a particular point in an article under question. Providing intuitive ways to link to article excerpts from summaries would allow individuals to, when necessary, encounter extra context around a particular point to judge credibility and accuracy.

Participants' mitigation strategy of acting as information mediaries to add subjective context to statistical health information aligns with theories of "gist information," which purports that subjective, meaningful, interpretations of information are more likely to be shared online than objective, decontextualized, facts [9–11]. Future work should consider if gist information is a way to provide more complete, accurate, and more emotionally accessible information to people with neurodegenerative conditions.

5.2.2 Considering Design as a Credibility Indicator. Past work has investigated different structural indicators of reliable versus unreliable health information by investigating article titles [17], writing style and sentiment [25], as well as Document Object Mode corpora, word-level content and link corpora [99]. Web-page design may be an additional credibility indicator, as this was a particularly salient factor for information verification for participants in our study. Content at the bottom of an article in a similar shape and position as advertisements inspired distrust. Additionally, designs which required readers to submit personal details, which is typical for medical clinic websites to recruit further clinical trial participants, inspired distrust for readers with dementia as it indicated the authors have "another agenda." Similarly, when resources required subscriptions to read a published research article, as most academic journals and conferences do, this also indicated alternative motivation, inspiring distrust. This demonstrates that even credible online health information resources may be inadvertently inspiring distrust in readers due to these design aspects. This has implications for information authors to consider the design of online informational resources with careful consideration for how web-page designs may be perceived by the intended readers.

5.2.3 Facilitating Peer Consultation of Credibility. Participants assessed credibility by consulting peers to collaboratively analyze online health resources. This included posting information on social media to warn others of potential scams and exploitative content as well as seeking these warnings from others. In this way, participants were acting as cybersecurity advocates [30, 31] or guardians [36] by taking it upon themselves to inform others of dementia-related health scams and exploitation. As previous work has noted, acting as a cybersecurity guardian/advocate serves a meaningful role in society, which can have positive impacts on mental well-being [62] and lead to self-efficacy and self-worth [31]. With past work finding people experiencing age-related cognitive changes primarily rely on caregivers to establish cybersecurity safe-guards on their behalf [54, 55], our work provides a contrasting perspective, expanding the potential role people with age-related cognitive changes may play in the design of future tools to identify online misinformation.

In noting this role, we do not minimize the risks of individuals with neurodegenerative conditions verifying scams, as people with dementia can experience impaired judgement [60]. Participants noted this risk when describing relying on anecdotal health information and testimonials from others with dementia. One potential safeguard is to follow a "shared governance" model, where professional moderators combat misinformation within an online community along-side "senior peers" with dementia and other community members [43].

6 CONCLUSION

Through an action research approach involving interviews and observation sessions with sixteen people with mild to moderate dementia, this work details barriers surrounding dementia-related information, including: the lack of relevant information, inaccessible information formats, inaccurate and oversimplified information, as well as information which elicited distrust. In response to these barriers, findings from this study showed people with dementia employed a variety of mitigation strategies. Based on these findings, this paper makes two primary contributions to the literature. First, it identifies the barriers people are facing - and the solutions that they have successfully employed - providing cognitive accessibility researchers with opportunities to design future technical interventions to make online health information more accessible and credible to neurodiverse populations. Second, it demonstrates the agency with which people with dementia find work-arounds to the online health information barriers they face.

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REFERENCES

[1] Alzheimer's Association. Younger/Early-Onset Alzheimer's. Alzheimer's Disease and Dementia. Retrieved March 16, 2020 from https://alz.org/alzheimers-dementia/what-is-alzheimers/younger-early-onset

[2] Alzheimer's Association. 2021. *2021 Alzheimer's Disease Facts and Figures.* Alzheimers Dement, Chicago, IL.

[3] Faranak Aminzadeh, Anna Byszewski, Frank J. Molnar, and Marg Eisner. 2007. Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging & Mental Health* 11, 3: 281–290. https://doi.org/10.1080/13607860600963695

[4] Laima Augustaitis, Leland A. Merrill, Kristi E Gamarel, and Oliver L. Haimson. 2021. Online Transgender Health Information Seeking: Facilitators, Barriers, and Future Directions. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–14. Retrieved December 18, 2021 from https://doi.org/10.1145/3411764.3445091

[5] Nina Baruch, Charlotte L. Allan, Samuel Cundell, Samuel Clark, and Brian Murray. 2017. Promoting early dementia diagnosis: a video designed by patients, for patients. *International Psychogeriatrics* 29, 5: 863–867.

[6] Susan Behuniak. 2011. The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society* 31: 70–92. https://doi.org/10.1017/S0144686X10000693

[7] Gerd Berget. 2020. "Information Needs of the End Users Have Never Been Discussed": An Investigation of the User-intermediary Interaction of People with Intellectual Impairments. In *Proceedings of the 2020 Conference on Human Information Interaction and Retrieval* (CHIIR '20), 93–102. https://doi.org/10.1145/3343413.3377953

[8] Talita Britto and Ednaldo Pizzolato. 2016. Towards Web Accessibility Guidelines of Interaction and Interface Design for People with Autism Spectrum Disorder.

[9] David A. Broniatowski and Valerie F. Reyna. 2013. Gist and Verbatim in Narrative Memory. In *2013 Workshop on Computational Models of Narrative* (OpenAccess Series in Informatics (OASIcs)), 43–51. https://doi.org/10.4230/OASIcs.CMN.2013.43

[10] David A. Broniatowski and Valerie F. Reyna. 2015. Formalizing Risky Choice with a Logistic Model of Fuzzy Trace Theory. In *Proceedings of the 37th Annual Meeting of the Cognitive Science Society.*

[11] David A. Broniatowski and Valerie F. Reyna. 2020. To illuminate and motivate: a fuzzy-trace model of the spread of information online. *Computational and Mathematical Organization Theory* 26, 4: 431–464. https://doi.org/10.1007/s10588-019-09297-2

[12] Isabel Cachola, Kyle Lo, Arman Cohan, and Daniel Weld. 2020. TLDR: Extreme Summarization of Scientific Documents. In *Findings of the Association for Computational Linguistics: EMNLP 2020*, 4766–4777. https://doi.org/10.18653/v1/2020.findings-emnlp.428

[13] Ruth Chaplin and Ian Davidson. 2016. What are the experiences of people with dementia in employment? *Dementia* 15, 2: 147–161. https://doi.org/10.1177/1471301213519252

[14] Kathy Charmaz. 2014. Constructing Grounded Theory: A practical guide through qualitative analysis. SAGE, London.

[15] CHI 2021 Paper Chairs. 2020. Some Insights on CHI 2021 Paper Lengths. *CHI2021 | May 8-13, Yokohama, Japan.* Retrieved December 23, 2021 from http://chi2021.acm.org/

[16] Denise Craig and Edward Strivens. 2016. Facing the times: A young onset dementia support group: FacebookTM style. *Australasian Journal on Ageing* 35, 1: 48–53. https://doi.org/10.1111/ajag.12264

[17] Sameer Dhoju, Md Main Uddin Rony, Muhammad Ashad Kabir, and Naeemul Hassan. 2019. Differences in Health News from Reliable and Unreliable Media. In *Companion Proceedings of The 2019 World Wide Web Conference* (WWW '19), 981–987. https://doi.org/10.1145/3308560.3316741

[18] Mark Diaz, Isaac Johnson, Amanda Lazar, Anne Marie Piper, and Darren Gergle. 2018. Addressing Age-Related Bias in Sentiment Analysis. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, 1–14. https://doi.org/10.1145/3173574.3173986

[19] Emma Dixon and Amanda Lazar. 2020. The Role of Sensory Changes in Everyday Technology use by People with Mild to Moderate Dementia. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility* (ASSETS '20), 1–12. https://doi.org/10.1145/3373625.3417000

[20] Emma Dixon, Anne Marie Piper, and Amanda Lazar. 2021. "Taking care of myself as long as I can": How People with Dementia Configure Self-Management Systems. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–14. https://doi.org/10.1145/3411764.3445225

[21] Perry Edelman, Daniel Kuhn, Bradley R. Fulton, and Gregory A. Kyrouac. 2006. Information and Service Needs of Persons With Alzheimer's Disease and Their Family Caregivers Living in Rural Communities. *American Journal of Alzheimer's Disease & Other Dementias®* 21, 4: 226–233. https://doi.org/10.1177/1533317506290664

[22] David Evans. 2019. An exploration of the impact of younger-onset dementia on employment. *Dementia* 18, 1: 262–281. https://doi.org/10.1177/1471301216668661

[23] Dorothy Forbes, Sara Finkelstein, Catherine Blake, Maggie Gibson, Debra Morgan, Maureen Markle-Reid, Ivan Culum, and Emily Thiessen. 2012. Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. *Rural and Remote Health.* https://doi.org/10.22605/RRH2201

[24] Ed Freeman, Linda Clare, Nada Savitch, Lindsay Royan, Rachael Litherland, and Margot Lindsay. 2005. Improving website accessibility for people with

early-stage dementia: A preliminary investigation. *Aging & Mental Health* 9, 5: 442–448. https://doi.org/10.1080/13607860500142838

[25] Amira Ghenai and Yelena Mejova. 2018. Fake Cures: User-centric Modeling of Health Misinformation in Social Media. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW: 58:1-58:20. https://doi.org/10.1145/3274327

[26] Ryan Colin Gibson, Mark D. Dunlop, Matt-Mouley Bouamrane, and Revathy Nayar. 2020. Designing Clinical AAC Tablet Applications with Adults who have Mild Intellectual Disabilities. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–13. Retrieved January 10, 2022 from https://doi.org/10.1145/3313831.3376159

[27] Sarah A. Gilbert, Casey Fiesler, Lindsay Blackwell, Michael Ann DeVito, Michaelanne Dye, Shamika Goddard, Kishonna L. Gray, David Nemer, and C. Estelle Smith. 2020. Public Scholarship and CSCW: Trials and Twitterations. In *Conference Companion Publication of the 2020 on Computer Supported Cooperative Work and Social Computing*, 447–456. Retrieved January 10, 2022 from https://doi.org/10.1145/3406865.3418589

[28] Jose Guzman-Parra, Pilar Barnestein-Fonseca, Gloria Guerrero-Pertiñez, Peter Anderberg, Luis Jimenez-Fernandez, Esperanza Valero-Moreno, Jessica Marian Goodman-Casanova, Antonio Cuesta-Vargas, Maite Garolera, Maria Quintana, Rebeca I García-Betances, Evi Lemmens, Johan Sanmartin Berglund, and Fermin Mayoral-Cleries. 2020. Attitudes and Use of Information and Communication Technologies in Older Adults With Mild Cognitive Impairment or Early Stages of Dementia and Their Caregivers: Cross-Sectional Study. *Journal of Medical Internet Research* 22, 6: e17253. https://doi.org/10.2196/17253

[29] Duke Han, Patricia Boyle, Bryan James, Lei Yu, and David Bennett. 2015. Mild Cognitive Impairment and Susceptibility to Scams in Old Age. *Journal of Alzheimer’s disease: JAD* 49, 3: 845–851. https://doi.org/10.3233/JAD-150442

[30] Julie M. Haney and Wayne G. Lutters. 2018. “It’s Scary. . .It’s Confusing. . .It’s Dull”: How Cybersecurity Advocates Overcome Negative Perceptions of Security. 411–425. Retrieved June 30, 2021 from https://www.usenix.org/conference/soups2018/presentation/haney-perceptions

[31] Julie M. Haney and Wayne G. Lutters. 2019. Motivating Cybersecurity Advocates: Implications for Recruitment and Retention. In *Proceedings of the 2019 on Computers and People Research Conference* (SIGMIS-CPR ’19), 109–117. https://doi.org/10.1145/3322385.3322388

[32] Juliet Harland, Peter Bath, and Ann Wainwright. 2017. Making sense of dementia: a phenomenographic study of the information behaviours of people diagnosed with dementia. *Aslib Journal of Information Management,* 69, 3: 261–277.

[33] Gillian R. Hayes. 2011. The relationship of action research to human-computer interaction. *ACM Transactions on Computer-Human Interaction* 18, 3: 15:1-15:20. https://doi.org/10.1145/1993060.1993065

[34] Soumya Hegde and Ratnavalli Ellajosyula. 2016. Capacity issues and decision-making in dementia. *Annals of Indian Academy of Neurology* 19, Suppl 1: S34–S39. https://doi.org/10.4103/0972-2327.192890

[35] Niels Hendriks, Liesbeth Huybrechts, Andrea Wilkinson, and Karin Slegers. 2014. Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference on Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - PDC ’14 - volume 2*, 33–36. https://doi.org/10.1145/2662155.2662196

[36] Meghan E Hollis, Marcus Felson, and Brandon C Welsh. 2013. The capable guardian in routine activities theory: A theoretical and conceptual reappraisal. *Crime Prevention and Community Safety* 15, 1: 65–79. https://doi.org/10.1057/cpcs.2012.14

[37] Thomas Howard, Krishna Venkatasubramanian, Jeanine L M Skorinko, Pauline Bosma, John Mullaly, Brian Kelly, Deborah Lloyd, Mary Wishart, Emiton Alves, Nicole Jutras, Mariah Freark, and Nancy A. Alterio. 2021. Designing an App to Help Individuals with Intellectual and Developmental Disabilities to Recognize Abuse. In *The 23rd International ACM SIGACCESS Conference on Computers and Accessibility* (ASSETS ’21), 1–14. https://doi.org/10.1145/3441852.3471217

[38] Ruimin Hu and Jinjuan Heidi Feng. 2015. Investigating Information Search by People with Cognitive Disabilities. *ACM Transactions on Accessible Computing* 7, 1: 1–30. https://doi.org/10.1145/2729981

[39] Innovations in Dementia. Dementia Engagement and Empowerment Project (DEEP). *DEEP*. Retrieved September 9, 2021 from https://www.dementiavoices.org.uk/

[40] iSpeech. 2018. iSpeech Web Reader: Make Your Website Talk| Site Text to Speech. Retrieved January 10, 2022 from https://www.ispeech.org/webapps/webreader

[41] Gavindya Jayawardena, Anne Michalek, Andrew Duchowski, and Sampath Jayarathna. 2020. Pilot Study of Audiovisual Speech-In-Noise (SIN) Performance of Young Adults with ADHD. In *ACM Symposium on Eye Tracking Research and Applications* (ETRA ’20 Short Papers), 1–5. https://doi.org/10.1145/3379156.3391373

[42] Jazette Johnson, Rebecca W. Black, Yunan Chen, and Gillian R. Hayes. 2019. Older Adults with Dementia in an Online Forum: A Preliminary Analysis. In *Conference Companion Publication of the 2019 on Computer Supported Cooperative Work and Social Computing* (CSCW ’19), 231–235. https://doi.org/10.1145/3311957.3359477

[43] Jazette Johnson, Rebecca W. Black, and Gillian R. Hayes. 2020. Roles in the Discussion: An Analysis of Social Support in an Online Forum for People with Dementia. *Proceedings of the ACM on Human-Computer Interaction* 4, CSCW2: 1–30. https://doi.org/10.1145/3415198

[44] Bridget Jones, Heather Gage, Christian Bakker, Helena Barrios, Sarah Boucault, Johannes Mayer, Anna Metcalfe, Joany Millenaar, Wendy Parker, and Anneli Orrung Wallin. 2018. Availability of information on young onset dementia for patients and carers in six European countries. *Patient Education and Counseling* 101, 1: 159–165. https://doi.org/10.1016/j.pec.2017.07.013

[45] Holtzblatt Karen and Jones Sandra. 1993. Contextual Inquiry: A Participatory Technique for System Design. In *Participatory Design*. CRC Press.

[46] Nana Kesewaa Dankwa. 2021. “All Names are Pseudonyms”: A Critical Reflection on Pseudonymizing Names in HCI: “All Names are Pseudonyms.” In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–6. Retrieved January 10, 2022 from https://doi.org/10.1145/3411763.3450376

[47] Al Majed Khan, Dr Mark D. Dunlop, Dr Marilyn Lennon, and Dr Mateusz Dubiel. 2021. Towards Designing Mobile Apps for Independent Travel: Exploring Current Barriers and Opportunities for Supporting Young Adults with Down’s Syndrome. *ACM Transactions on Accessible Computing* 14, 3: 13:1-13:40. https://doi.org/10.1145/3460943

[48] Nikki Hei Tong Lam and Benjamin K. P. Woo. 2020. YouTube as a New Medium for Dementia Education Among Chinese Americans. *Community Mental Health Journal* 56, 3: 435–439. https://doi.org/10.1007/s10597-019-00493-7

[49] Amanda Lazar and Emma E. Dixon. 2019. Safe Enough to Share: Setting the Dementia Agenda Online. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW: 1–23. https://doi.org/10.1145/3359187

[50] Kelly Mack, Emma McDonnell, Dhruv Jain, Lucy Lu Wang, Jon E. Froehlich, and Leah Findlater. 2021. What Do We Mean by “Accessibility Research”? A Literature Survey of Accessibility Papers in CHI and ASSETS from 1994 to 2019. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–18. Retrieved November 28, 2021 from https://doi.org/10.1145/3411764.3445412

[51] Aarti Malhotra, Lifei Yu, Tobias Schroder, and Jesse Hoey. 2015. An exploratory study into the use of an emotionally aware cognitive assistant. *Association for the Advancement of Artificial Intelligence*: 6.

[52] Nora McDonald, Allison Battisti, Galina Madjaroff, and Helena Mentis. 2020. Realizing Choice: Online Safeguards for Couples Adapting to Cognitive Challenges. In *Proceedings of the Sixteenth Symposium on Usable Privacy and Security*, 13. https://doi.org/978-1-939133-16-8

[53] Nora Mcdonald and Helena M. Mentis. 2021. “Citizens Too”: Safety Setting Collaboration Among Older Adults with Memory Concerns. *ACM Transactions on Computer-Human Interaction* 28, 5: 1–32. https://doi.org/10.1145/3465217

[54] Helena M. Mentis, Galina Madjaroff, and Aaron K. Massey. 2019. Upside and Downside Risk in Online Security for Older Adults with Mild Cognitive Impairment. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI ’19*, 1–13. https://doi.org/10.1145/3290605.3300573

[55] Helena M. Mentis, Galina Madjaroff, Aaron Massey, and Zoya Trendafilova. 2020. The Illusion of Choice in Discussing Cybersecurity Safeguards Between Older Adults with Mild Cognitive Impairment and Their Caregivers. *Proceedings of the ACM on Human-Computer Interaction* 4, CSCW2: 1–19. https://doi.org/10.1145/3415235

[56] Anne M. P. Michalek, Silvana M. Watson, Ivan Ash, Stacie Ringleb, and Anastasia Raymer. 2014. Effects of noise and audiovisual cues on speech processing in adults with and without ADHD. *International Journal of Audiology* 53, 3: 145–152. https://doi.org/10.3109/14992027.2013.866282

[57] Lourdes Moreno, Rodrigo Alarcon, and Paloma Martínez. 2021. Designing and Evaluating a User Interface for People with Cognitive Disabilities. In *Proceedings of the XXI International Conference on Human Computer Interaction* (Interacción ’21), 1–8. https://doi.org/10.1145/3471391.3471400

[58] National Centers for Chronic Disease Prevention and Health Promotion. 2020. Health Equity | CDC. Retrieved August 25, 2021 from https://www.cdc.gov/chronicdisease/healthequity/index.htm

[59] National Council of Dementia Minds. 2021. Dementia Minds - Insights of Persons Living Well with Neurocognitive Disorders. Retrieved March 8, 2022 from https://dementiaminds.org/dementia-minds/

[60] National Institute of Health. 2017. Home Safety and Alzheimer’s Disease. *National Institute on Aging*. Retrieved April 4, 2020 from https://www.nia.nih.gov/health/home-safety-and-alzheimers-disease

[61] NeuroQ. NeuroQ | Brain Health Supplements | Improved Cognitive Health. *NeuroQ*. Retrieved September 3, 2021 from https://neuroq.com/

[62] James Nicholson, Ben Morrison, Matt Dixon, Jack Holt, Lynne Coventry, and Jill McGlasson. 2021. Training and Embedding Cybersecurity Guardians in Older Communities. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–15. Retrieved June 30, 2021 from https://doi.org/10.1145/3411764.3445078

[63] Christina Nicolaidis (ed.). 2022. Manuscript Submission Guidelines and Policies for Autism in Adulthood.

[64] Hyunjin Noh and Jung Kwak. 2018. End-of-life decision making for persons with dementia: Proxies’ perception of support. *Dementia* 17, 4: 478–493. https://doi.org/10.1177/1471301216648473

[65] Redhwan Nour. 2015. Web searching by individuals with cognitive disabilities. *ACM SIGACCESS Accessibility and Computing*, 111: 19–25. https://doi.org/10.1145/2809904.2809909

[66] Norbert Nthala and Ivan Flechais. 2018. Informal Support Networks: an investigation into Home Data Security Practices. 63–82. Retrieved June 30, 2021 from https://www.usenix.org/conference/soups2018/presentation/nthala

[67] Anna Offenwanger, Alan John Milligan, Minsuk Chang, Julia Bullard, and Dongwook Yoon. 2021. Diagnosing Bias in the Gender Representation of HCI Research Participants: How it Happens and Where We Are. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–18. Retrieved December 23, 2021 from https://doi.org/10.1145/3411764.3445383

[68] Nikolay Pavlov. 2014. User Interface for People with Autism Spectrum Disorders. *Journal of Software Engineering and Applications* 2014. https://doi.org/10.4236/jsea.2014.72014

[69] James W. Pennebaker,. *The LIWC API*. Receptiviti. Retrieved June 25, 2021 from https://www.receptiviti.com/liwc

[70] Rosalind W. Picard. 2000. *Affective Computing*. MIT Press.

[71] Anne Marie Piper, Raymundo Cornejo, Lisa Hurwitz, and Caitlin Unumb. 2016. Technological Caregiving: Supporting Online Activity for Adults with Cognitive Impairments. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems - CHI '16*, 5311–5323. https://doi.org/10.1145/2858036.2858260

[72] Lev Poretski, Taamannae Taabassum, and Anthony Tang. 2021. Immigrant Families' Health-Related Information Behavior on Instant Messaging Platforms: Health-related Information Exchange in Immigrant Family Groups on Instant Messaging Platforms. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–6. Retrieved December 18, 2021 from https://doi.org/10.1145/3411763.3451751

[73] Postlight. 2022. Mercury. *Mercury by Postlight*. Retrieved January 10, 2022 from https://mercury.postlight.com/

[74] Shibley Rahman and Kate Swaffer. 2018. Assets-based approaches and dementia-friendly communities. *Dementia* 17, 2: 131–137. https://doi.org/10.1177/1471301217751533

[75] Dora M. Raymaker, Steven K. Kapp, Katherine E. McDonald, Michael Weiner, Elesia Ashkenazy, and Christina Nicolaidis. 2019. Development of the AASPIRE Web Accessibility Guidelines for Autistic Web Users. *Autism in Adulthood* 1, 2: 146–157. https://doi.org/10.1089/aut.2018.0020

[76] Luz Rello and Ricardo Baeza-Yates. 2013. Good fonts for dyslexia. In *Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility* (ASSETS '13), 1–8. https://doi.org/10.1145/2513383.2513447

[77] Tania Rocha, Diana Carvalho, Maximino Bessa, Sofia Reis, and Lu´ıs Magalhaes. 2017. Usability evaluation of navigation tasks by people with intellectual disabilities: a Google and SAPO comparative study regarding different interaction modalities. *Universal Access in the Information Society* 16, 3: 581-592. https://doi.org/10.1007/s10209-016-0489-5

[78] Jason Rodriquez. 2013. Narrating Dementia: Self and Community in an Online Forum. *Qualitative Health Research* 23, 9: 1215–1227. https://doi.org/10.1177/1049732313501725

[79] Hanna Schäfer, Santiago Hors-Fraile, Raghav Pavan Karumur, André Calero Valdez, Alan Said, Helma Torkamaan, Tom Ulmer, and Christoph Trattner. 2017. Towards Health (Aware) Recommender Systems. In *Proceedings of the 2017 International Conference on Digital Health* (DH '17), 157–161. https://doi.org/10.1145/3079452.3079499

[80] Ari Schlesinger, W. Keith Edwards, and Rebecca E. Grinter. 2017. Intersectional HCI: Engaging Identity through Gender, Race, and Class. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17), 5412–5427. https://doi.org/10.1145/3025453.3025766

[81] Sara Shu and Benjamin K. P. Woo. 2020. Digital Media as a Proponent for Healthy Aging in the Older Chinese American Population: Longitudinal Analysis. *JMIR Aging* 3, 1: e20321. https://doi.org/10.2196/20321

[82] Sara Shu and Benjamin K. P. Woo. 2020. The Roles of YouTube and WhatsApp in Dementia Education for the Older Chinese American Population: Longitudinal Analysis. *JMIR Aging* 3, 1: e18179. https://doi.org/10.2196/18179

[83] Fabiola Silvaggi, Matilde Leonardi, Pietro Tiraboschi, Cristina Muscio, Claudia Toppo, and Alberto Raggi. 2020. Keeping People with Dementia or Mild Cognitive Impairment in Employment: A Literature Review on Its Determinants. *International Journal of Environmental Research and Public Health* 17, 3: 842. https://doi.org/10.3390/ijerph17030842

[84] Laurianne Sitbon, Andrew Bayor, Filip Bircanin, Stewart Koplick, and Margot Brereton. 2018. An Exploration of How People with Intellectual Disability Engage with Online Information Retrieval. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems* (CHI EA '18), 1–6. https://doi.org/10.1145/3170427.3188599

[85] Laurianne Sitbon and Margot Brereton. 2020. Co-design to Include Users with Intellectual Disability in Information Interaction Research. In *Proceedings of the 2020 Conference on Human Information Interaction and Retrieval* (CHIIR '20), 481–483. https://doi.org/10.1145/3343413.3378019

[86] Karin Slegers, Andrea Wilkinson, and Niels Hendriks. 2013. Active collaboration in healthcare design: participatory design to develop a dementia care app. In *CHI '13 Extended Abstracts on Human Factors in Computing Systems* (CHI EA '13), 475–480. https://doi.org/10.1145/2468356.2468440

[87] Aijia Soong, Shu Ting Au, Bhone Myint Kyaw, Yin Leng Theng, and Lorainne Tudor Car. 2020. Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: a scoping review. *BMC Geriatrics* 20, 1: 1–17. https://doi.org/10.1186/s12877-020-1454-y

[88] Kevin M Storer, Harini Sampath, and M. Alice Alice Merrick. 2021. "It's Just Everything Outside of the IDE that's the Problem": Information Seeking by Software Developers with Visual Impairments. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–12. Retrieved December 18, 2021 from https://doi.org/10.1145/3411764.3445090

[89] Manuka Stratta, Julia Park, and Cooper deNicola. 2020. Automated Content Warnings for Sensitive Posts. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems* (CHI EA '20), 1–8. https://doi.org/10.1145/3334480.3383029

[90] Kate Swaffer. 2015. Dementia and Prescribed Disengagement$^{\text{TM}}$. *Dementia* 14, 1: 3–6. https://doi.org/10.1177/1471301214548136

[91] Catherine V. Talbot, Siobhan T. O'Dwyer, Linda Clare, Janet Heaton, and Joel Anderson. 2020. How people with dementia use twitter: A qualitative analysis. *Computers in Human Behavior* 102: 112–119. https://doi.org/10.1016/j.chb.2019.08.005

[92] Weizhou Tang, Kate Olscamp, Seul Ki Choi, and Daniela B. Friedman. 2017. Alzheimer's Disease in Social Media: Content Analysis of YouTube Videos. *Interactive Journal of Medical Research* 6, 2: e19. https://doi.org/10.2196/ijmr.8612

[93] The Health Research Authority. 2005. *Mental Capacity Act*. Retrieved June 29, 2021 from https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/mental-capacity-act/

[94] Bronwen Thomas. 2017. Whose Story is it Anyway? Following Everyday Accounts of Living with Dementia on Social Media. *Style* 51, 3: 357–373.

[95] Virpi Timonen, Geraldine Foley, and Catherine Conlon. 2018. Challenges When Using Grounded Theory: A Pragmatic Introduction to Doing GT Research. *International Journal of Qualitative Methods* 17, 1: 1609406918758086. https://doi.org/10.1177/1609406918758086

[96] Jeanne Tyrrell, Nathalie Genin, and Michele Myslinski. 2006. Freedom of choice and decision-making in health and social care: Views of older patients with early-stage dementia and their carers. *Dementia* 5, 4: 479–502. https://doi.org/10.1177/1471301206069915

[97] UC Davis Alzheimer's Disease Center. 2002. Policy and Procedures for Assessing Capacity To Consent for Research. Retrieved from https://health.ucdavis.edu/clinicaltrials/StudyTools/Documents/ResearchCapacityPolicy7=02.pdf

[98] United Nations. Convention on the Rights of Persons with Disabilities (CRPD). Retrieved October 1, 2020 from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

[99] Rishabh Upadhyay, Gabriella Pasi, and Marco Viviani. 2021. Health Misinformation Detection in Web Content: A Structural-, Content-based, and Context-aware Approach based on Web2Vec. In *Proceedings of the Conference on Information Technology for Social Good* (GoodIT '21), 19–24. https://doi.org/10.1145/3462203.3475898

[100] US Government: General Services Administration. 2011. Federal Plain Language Guidelines. 118.

[101] Krishna Venkatasubramanian, Jeanine L. M. Skorinko, Mariam Kobeissi, Brittany Lewis, Nicole Jutras, Pauline Bosma, John Mullaly, Brian Kelly, Deborah Lloyd, Mariah Freark, and Nancy A. Alterio. 2021. Exploring A Reporting Tool to Empower Individuals with Intellectual and Developmental Disabilities to Self-Report Abuse. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–13. Retrieved November 28, 2021 from https://doi.org/10.1145/3411764.3445150

[102] Ruolin Wang, Zixuan Chen, Mingrui Ray Zhang, Zhaoheng Li, Zhixiu Liu, Zihan Dang, Chun Yu, and Xiang "Anthony" Chen. 2021. Revamp: Enhancing Accessible Information Seeking Experience of Online Shopping for Blind or Low Vision Users. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems* (CHI '21), 1–14. https://doi.org/10.1145/3411764.3445547

[103] Daniel Wessel, Ann-Kathrin Kennecke, and Moreen Heine. 2021. WCAG and Dyslexia; Improving the Search Function of Websites for Users With Dyslexia (Without Making It Worse for Everyone Else). In *Mensch und Computer 2021* (MuC '21), 168–179. https://doi.org/10.1145/3473856.3473867

[104] Carol Whitlatch. 2017. Meeting the Informational, Educational, and Psychosocial Support Needs of Persons Living With Dementia and Their Family Caregivers. *The Gerontologist*. https://doi.org/10.1093/geront/gnx162

[105] Benjamin K. P. Woo. 2018. An evaluation of YouTube in disseminating dementia knowledge to older Chinese in Britain. *International Psychogeriatrics* 30, 10: 1575. https://doi.org/10.1017/S1041610218000224

[106] World Health Organization. 2019. Dementia. *World Health Organization*. Retrieved April 2, 2020 from https://www.who.int/news-room/fact-sheets/detail/dementia

[107] Keke Wu, Emma Petersen, Tahmina Ahmad, David Burlinson, Shea Tanis, and Danielle Albers Szafir. 2021. Understanding Data Accessibility for People with

Intellectual and Developmental Disabilities. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–16. Retrieved December 18, 2021 from https://doi.org/10.1145/3411764.3445743

[108] Hannah Zeilig. 2014. Dementia As a Cultural Metaphor. *The Gerontologist* 54, 2: 258–267. https://doi.org/10.1093/geront/gns203

[109] Yan Zhang and Shijie Song. 2020. Older Adults' Evaluation of the Credibility of Online Health Information. In *Proceedings of the 2020 Conference on Human Information Interaction and Retrieval* (CHIIR '20), 358–362. https://doi.org/10.1145/3343413.3377997

[110] Xin Zheng, Jamie O. P. Chung, and Benjamin K. P. Woo. 2016. Exploring the Impact of a Culturally Tailored Short Film in Modifying Dementia Stigma Among Chinese Americans: A Pilot Study. *Academic Psychiatry: The Journal of the American Association of Directors of Psychiatric Residency Training and the Association for Academic Psychiatry* 40, 2: 372–374. https://doi.org/10.1007/s40596-015-0397-7

[111] Xin Zheng and Benjamin K. P. Woo. 2017. E-mental health in ethnic minority: A comparison of youtube and talk-based educational workshops in dementia. *Asian Journal of Psychiatry* 25: 246–248. https://doi.org/10.1016/j.ajp.2016.12.002