## "You Can't Ignore a Number This Big": Gender, Risk, and Responsibility in Online Advocacy for Women's Brain Health

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Victoria Mohr<sup>I</sup>, Annelies Kleinherenbrink<sup>I</sup>, and Piia Varis<sup>I</sup>

#### **Abstract**

Alzheimer's disease affects more women than men and has therefore been highlighted as a women's issue. However, there is much debate regarding the nature of this gap, with some studies pointing to sex/gender differences in longevity to explain the disparity. Against this background of empirical uncertainty, we ask how online women's brain health campaigns position women as specifically at risk of developing the disease. Using a multimodal approach, we examine how these platforms relate womanhood to risk, prevention, and responsibility. Four main themes emerged: risk quantification, risk management, risk dispersion, and the gendering of risk. We confirm previous studies that identified a dual discourse in which Alzheimer's is represented as both a catastrophic threat and as a fate that individuals can and must prevent. We find that both constructions are intensified on women-oriented platforms compared with nonspecific websites. Ethical implications of the individualization and gendering of risk and responsibility are discussed.

## **Keywords**

Alzheimer's; risk; gender; online health communication; online advocacy; websites; multimodality; qualitative research; discourse analysis; North America; Western Europe

In recent years, the internet has become integral to all aspects of our lives, including our health. Health information is increasingly spread and accessed online, allowing for health communication to take on a new and multimodal form. In this study, we analyze information published on online, English-language platforms of nonprofit organizations that target a general audience to raise awareness and disperse information about women's brain health. More specifically, we analyze websites that address women and Alzheimer's disease, which has been highlighted as a quintessential contemporary women's health issue.

Alzheimer's disease is responsible for roughly 70% of all dementia cases (Mielke et al., 2014). This irreversible and progressive neurodegenerative syndrome affects millions and has a devastating impact on sufferers' daily life and independence. Moreover, it has had a large impact on informal caregivers and health care costs, particularly in countries with aging populations. It is generally acknowledged in Alzheimer's research and treatment that more women suffer from the disease than men, that is, there is a higher prevalence rate in women. This rate is generally reported as approximately two thirds of sufferers, or up to 70% (this statistic varies slightly depending on region and research design but is fairly consistent). Against this

background, Alzheimer's disease has been highlighted as a women's issue, and as a clear case in point of the general need for more biomedical sex difference research. However, there is much debate regarding the incidence rate of Alzheimer's in women versus men. Significant research has concluded that most if not all of the higher prevalence rate in women can be attributed to women's greater longevity—meaning that the incidence rate is the same in men and women and that the apparent sex/gender<sup>1</sup> gap is confounded by life expectancy (Edland et al., 2002; Fisher et al., 2018; Mielke et al., 2014; Moschetti et al., 2012). However, some research has also found evidence to the contrary, with some age-controlled studies still showing a rather large sex/gender gap (Fisher et al., 2018; Gao et al., 1998). Factors contributing to such contradictory findings include recent shifts in medical coding and issues regarding clinical diagnosis studies versus research focused on brain pathology (Fisher et al., 2018). Furthermore, if there is a true disparity in incidence, the

<sup>1</sup>Tilburg University, Tilburg, The Netherlands

#### **Corresponding Author:**

Annelies Kleinherenbrink, Department of Culture Studies, PO box 90153, 5000 LE Tilburg, The Netherlands. Email: a.v.kleinherenbrink@tilburguniversity.edu

causes behind this are elusive. Overall, the biological mechanisms behind Alzheimer's disease are poorly understood, and this is particularly the case when it comes to sex/gender-based differences in risk and pathology. Research has shown sex/gender-based differences in symptoms and development of the disease, but it has not been established whether or not these can be tied to higher incidence (Fisher et al., 2018; Mielke et al., 2014). Thus, the question remains in what sense Alzheimer's is specifically a women's issue.

Against this background of empirical uncertainty, we ask how women are positioned as specifically at risk of developing the disease and which norms and subject positions are associated with this representation. Being cultural analysts (and not medical researchers or practitioners), we are less concerned with the true nature of, and causes behind, the sex/gender gap in Alzheimer's disease than with the discourse surrounding women's brain health. We hereby build on a large body of research that points to the gendering of risk, responsibility, and freedom in various health discourses. This research area has highlighted how hegemonic femininity is often reflected and constructed in public health messages, which may thereby affect women's self-perception and condition individual as well as collective action. Overall, these discourses tend to affirm stereotypical gender norms and emphasize individual responsibility over social change. Well-documented cases in point include sexual and reproductive health (e.g., Fage-Butler, 2017; Thomas & Lupton, 2016) and breast cancer (e.g., Gibson et al., 2014; King, 2006; Sulik, 2011). Given pervasive understandings of the brain as a sexed/gendered organ and of Alzheimer's disease as a women's issue, it is pertinent to examine women's brain health campaigns in light of these discursive trends. Thus, using a multimodal approach that examines text and image holistically, we consider to what extent and in which ways online women's brain health platforms frame risk and prevention of Alzheimer's disease in gendered and individualized terms. Before presenting our analysis, we will motivate and contextualize this focus in more detail.

## Sex, Gender, and Women's Health

Approaches to women's health in Western medicine have undergone a number of transformations in recent decades. Most notably, after women's health advocates successfully campaigned against women's exclusion from medical research in the United States, the scope of women's health broadened during the early 1990s from mainly reproductive issues (i.e., "bikini medicine") to encompass *all* aspects of health and disease. With this expanded notion of women's health, the focus came to be on a version of biological sex that was now

"understood as residing throughout a woman's body," and thereby as "the difference that most determines women's health" (Eckman, 1998, p. 141, our emphasis). This "mainstreaming" of sex-based biomedicine was further cemented by the landmark U.S. Institute of Medicine report Exploring the Biological Contributions to Human Health: Does Sex Matter? (Pardue & Wizemann, 2001), which highlights neuroscience as a particularly important area of interest and which declares that "[sex] matters in ways that we did not expect. Undoubtedly, it also matters in ways that we have not begun to imagine" because "every cell has a sex" (p. 4). Indicating that biological sex characterizes every fiber of our being, this phrase "every cell has a sex" has become an oft-repeated slogan within the contemporary women's health movement. For example, Janine Clayton, director of the U.S. National Institutes of Health Office of Research on Women's Health, used it in 2014 to promote new policies mandating all National Institutes of Health (NIH)-funded preclinical research to include sex as a biological variable (Rabin, 2014; see also Clayton & Collins, 2014). Policies such as these challenge a research tradition which predominantly relies on male nonhuman animals and tissues even in studies of diseases that primarily affect women (Beery & Zucker, 2011).

As this bias can lead to suboptimal diagnosis and treatment for women, few, if any, scientists disagree that biomedical science must become more inclusive by studying a wider variety of bodies. However, the focus on sex as a key determinant of women's health has also raised the concern "that one mistake, namely, treating males as the norm, will be replaced with another; namely, treating males and females as two distinct entities" (Fine et al., 2014, para. 2). This critique is especially pertinent to research on sex differences in the brain, where sociocultural influences are often conspicuously ignored and where findings of "biological difference" are easily abused in the public sphere to naturalize social inequalities between men and women (Fine, 2013; Maney, 2016). While sex-based medicine is often represented as a first step toward personalized medicine, it risks reifying the idea(l) of the average or typical woman by suggesting that all women share the same biomedical identity—thus setting up a norm that may prove difficult to move beyond or deconstruct again. Even though such essentialism might be used for merely strategical reasons—that is, to get women's health on the map with an apparently straightforward, common sense argument about sex differences—it goes against the long-standing recognition within feminist theory that there can be no single inclusive definition or universal experience of womanhood, be it biological or social (e.g., Crenshaw, 1989; Fausto-Sterling, 1993;

Spelman, 1988; Stone, 2007). Specifically, popular phrases like "female heart attacks" or "female brains" gloss over within-group variation and between-group overlap which may be clinically just as relevant as between-group differences and tend to use sex as a proxy for other more precise predictors of health outcomes (Maney, 2016; Richardson et al., 2015; Springer et al., 2012).

This context demonstrates the interplay between advocacy, policy, research, and ultimately clinical care. Research of online constructions of women's brain health will therefore provide further insights into how women's health advocacy relates womanhood to health and illness. In our analysis, we will examine the ways in which public health messages relate womanhood to risk as well as to the possibility of prevention.

# Prevention as an Individual Responsibility

Traditionally, the women's health movement has focused on the recognition that social inequalities shape women's well-being, as well as on the demedicalization of women's bodies and experiences, informed and participatory patienthood, and self-care (Eckman, 1998; Epstein, 2008; Kuhlmann, 2009). In today's mainstream Western culture, there is a proliferation of self-help discourses that encourage the consumption of medical knowledge and emphasize self-determination, but are largely divorced from feminist practices of social justice and collective political action. Instead, such discourses represent health primarily in terms of individual responsibility, with a strong focus on risk prevention through lifestyle optimizations supposedly available to anyone (Cederström & Spicer, 2018; Katz & Peters, 2008). For example, popular brain health discourses hold out the promise that "braintraining" exercises protect against psychological and neurological problems (Pitts-Taylor, 2010; Thornton, 2011). Several scholars have raised the concern that this emphasis on self-determination leads to victim-blaming and relieves governments from their duty to structurally address social ills (Broer & Pickersgill, 2015).

This individualization of responsibility seems directly linked to a specific conceptualization of risk. Ogden (1995) argues that toward the end of the 20th century, the notion of self-efficacy became central to theories of healthy behavior, and health psychologists started to conceptualize risk as a matter of our individual ability to avoid threats to health, rather than as the presence or absence of such threats per se. As a result, staying healthy was increasingly seen as a personal choice and even as a moral obligation, to be pursued through constant vigilance, engagement with expert advice, and self-control (Galvin, 2002; Greco, 1993). Health, then, has become

not so much about the absence of symptoms as about continuous monitoring and maintenance in the face of given external dangers: "to be health conscious today is to come into an understanding that one's health is in continuous jeopardy" (Crawford, 2006, p. 403). This "pursuit of healthiness," which has become a pervasive lifestyle within Western neoliberal societies, constructs a moral identity for the responsible citizen (Ayo, 2012).

Western media frame dementia, in particular, within such terms. For example, in an analysis of British newspapers, Peel (2014) identifies two discourses regarding dementia: one foregrounding it as a catastrophic epidemic and the other revolving around individual prevention. Peel argues that the latter message, which represents dementia as preventable and lifestyle optimization as individual duty, is particularly disconcerting as the causes of dementia are largely unknown. Lawless et al. (2018) identified a similar duality in a recent analysis of nonprofit Alzheimer's organizations' websites and further showed that specific rhetorical devices sustain these discourses. For example, they consider quantification (i.e., the presentation of risk in statistical terms) as a tool or pattern that interpellates audiences as individuals-at-risk and thereby compels them to take action, thus promoting a specific moral identity of the responsible subject.

In our analysis, we will pay specific attention to this role of quantification. Interestingly, Woodward (1999) has argued that the language of statistics does not guarantee action by itself because it "continuously offers itself up as a way of understanding our lives and the world" (p. 178) and thereby engenders "a structure of postmodern feeling that oscillates between urgency and boredom" (p. 193). That is, the constant confrontation with impending doom that characterizes our culture can inspire action or cynicism. As such, Woodward argues, activists and policy makers must find strategies to successfully induce "statistical panic," whereby "fatally, we feel that a certain statistic, which is in fact based on an aggregate and is only a measure of probability, actually represents our very future" (p. 185). In other words, the statistic is most effective when it is experienced as personal information. We want to suggest here that appealing to gender stereotypes can be one way to achieve this: by addressing women as women by invoking gender-stereotypical aesthetics and normativities, statistical panic can be "nichemarketed." In our analysis, we pay attention to if and how this plays out on women's brain health platforms. As such, this study extends recent qualitative analyses of risk and responsibility in discourses on dementia (Lawless et al., 2018; Peel, 2014) by focusing on the ways in which such meanings are constructed through the prescription of gender norms—and vice versa: how gender norms may be constructed through the prescription of certain health-related attitudes and behaviors.

## The Gendering of Online Health Information

Various studies have underlined the importance of the online dissemination of health-related knowledge. Even though online information does not *replace* the information provided by health care providers, it does influence health-related decisions and is often discussed by patients with their doctors (e.g., Caiata-Zufferey et al., 2010; Morahan-Martin, 2004; Schwartz et al., 2006; Strekalova, 2016). Charities such as the ones examined in this study are among the most visible online resources, in addition to medical institutions and pharmaceutical companies (Nettleton et al., 2005).

A meta-analysis by Hallyburton and Evarts (2014) suggests that women are somewhat more likely than men to seek out online health information. This outcome is not surprising, given the fact that communication and care-taking (for the self as well as for others) are typically regarded as belonging to the feminine domain, so that women are positioned not only as responsible for their own health but also as gatekeepers for their family's health (e.g., De Brun et al., 2013). In addition, it appears that online health information is often presented in gendered terms. Royal (2008), for example, presents qualitative evidence that popular lifestyle websites frame health information in terms of femininity, adopting a "women's magazine model" that reinforces their role as informal caregivers. Furthermore, critical discourse analyses of breast cancer campaigns have documented the reinforcement of sexist gender norms by women's health advocacy (e.g., Gibson et al., 2015; Haines et al., 2010). So-called "pink ribbon culture" portrays women as personally responsible for maintaining or regaining their health by consuming expert information, pursuing a healthy lifestyle, making donations, and having an optimistic attitude—all of which gets packaged in a hegemonically feminine aesthetic (Bell, 2010; Gibson et al., 2014; Sulik, 2011). Such discourses ultimately create an image of a woman who is continually at risk, whose purported freedom is to choose between a limited number of health-optimizing behaviors, and for whom collective empowerment and social change are scarcely on the agenda (Dubriwny, 2012; Riley et al., 2018).

In this study, we analyze to what extent online platforms for women's brain health relate to such constructions of health as something that can be achieved, and must constantly be aspired to, by any individual woman. We attend to ways in which hegemonic femininity may be used to get this message across and instill a sense of "statistical panic" in women. To this end, we will contrast general online platforms for Alzheimer's disease with platforms specifically aimed at Alzheimer's in women.

#### Method

This study analyzes five women-oriented websites dealing with Alzheimer's disease (Table 1) with five sex/gender nonspecific Alzheimer's and aging websites (Table 2) examined as a point of comparison. The selected sites were chosen for their focus on or significant resources directed at patients and other lay people (as opposed to doctors or researchers), perceived credibility, and financial significance. All U.S.-based nonprofit organizations selected, for example, are registered 501(c)3 charities, and most claim millions raised for Alzheimer's research (Internal Revenue Service, 2017, 2018, 2019a, 2019b). Only English-language websites were considered, which resulted in a preponderance of U.S.-based organizations.

Data were collected from January to March 2019 and thus are intended as a "snapshot" of what content was available on these sites during that time. Importantly, our analysis is not intended as a large-scale, comprehensive assessment of online dementia discourse-our convenience sample is of limited scope and sheds light on some, but not all, online health communication about women and Alzheimer's disease. Nor do we suggest that the targeted audience will necessarily take up the provided information with the meanings that we extract from it—reading is an active, interpretative practice which can involve acceptance as well as resistance or transformation and which depends heavily on the individual reader. However, through the comparative aspect of our analysis, we aim to reveal pervasive if subtle trends and tendencies in online health communication.

The selected platforms were approached using multimodal critical discourse analysis (MCDA). Almost all digital media rely on multimodal forms of communication, and thus analysis of online discourses demands a multimodal approach. In the context of this study, multimodality represents an understanding of both the communicative role and affordances of individual modes as well as their interaction to create a semiotic whole, as modes are "impossible to isolate" (Machin, 2016, p. 326). Critical analysis here is the situating of emerging multimodal discourses within the present and historical contexts of women's health as outlined in the introduction (Kress, 2010). It is an examination of what motivates these discourses in the context of charitable organizations, and what ideologies they may reflect given a larger neoliberal health care context. This study therefore utilizes MCDA in an effort to holistically and contextually examine the websites considered.

Previous research on health-related media has established the presence of public discourses on risk and neoliberal responsibilization regarding the brain and aging (Lawless et al., 2018; O'Connor & Joffe, 2015), increased

Table I. Women's Organizations.

Organization	URL	Organization Type	Country/Region
My Brain	mybrain.alz.org	Nonprofit—gender- specific subsite of Alzheimer's Association	United States
Women's Brain Health Initiative (WBHI)	womensbrainhealth.org	Nonprofit	Canada
Women and Alzheimer's	womenandalzheimers.org	Nonprofit—gender- specific subsite of Cure Alzheimer's Fund	United States
Women's Alzheimer's Movement (WAM)	thewomensalzheimersmovement.org	Nonprofit	United States
Women's Brain Project	womensbrainproject.com	Nonprofit	Switzerland

Table 2. Gender Nonspecific Organizations.

Organization	URL	Organization Type	Country/Region
Alzheimer's Association	alz.org	Nonprofit	United States
Alzheimer's UK	alzheimersresearchuk.org	Nonprofit	United Kingdom
Cure Alzheimer's Fund	https://curealz.org/	Nonprofit	United States
National Institute on Aging	www.nia.nih.gov	Government	United States
World Health Organization (WHO)	www.who.int	NGO	Global

Note.NGO = nongovernmental organization.

emphasis on these themes in women's health promotion discourses (Gibson et al., 2014, 2015), and the prevalence of these discourses particularly in online spaces (Harvey, 2013). Drawing on this research, the selected websites were subjected to an initial open code, which was then reviewed and refined to answer the following research questions:

**Research Question 1:** What, if any, representations of risk, prevention, and concepts of health versus illness in relation to sex/gender are present on these webpages?

**Research Question 2:** If present, how are these discursively organized?

Samples from the selected websites were collected and organized using Evernote software, which allows for the organization and tagging of full webpages as well as text and images. In an effort to address elements of priority and motivation inherent in the design of these websites, the home page was always considered first. Care was taken to capture any "slideshow" mechanisms or watch the full loop of any video or animation present on this page. From the front page, two directions were taken. First, the majority of the platforms considered had a "tab bar" across the top of their home page, with links to major pages or topics on the website. Each of the links on this

tab bar was opened and examined. Donation and contact pages were ignored as they typically do not contain any health information.

Second, any links from the front page (below the tab bar) were opened and sampled as appropriate. Any doubles from these two directions (i.e., any two links that led to the same page) were only sampled once. All of the websites considered offered a search function. For websites that were not sex/gender-specific, searches were conducted for the terms "women," "gender," and "sex differences" to ensure any relevant pages were included in the data. For websites that addressed women's health more generally, searches for the terms "Alzheimer's" and "dementia" were conducted. It was noted whether gender or Alzheimer's/dementia specific pages were found through the two link directions or through the search functionality, again in an effort to incorporate potentially motivated design choices.

Codes from the initial open code were then reviewed and organized into larger topics (e.g., use of statistics, images of older/younger women, representations of femininity) with an emphasis on those that were most prevalent across multiple platforms. The most prevalent topics were then analyzed and organized under the following overarching discursive themes: quantification of risk, risk management, risk dispersion, and the gendering of risk.

### Results

## Quantification of Risk

The first part of our analysis focuses on quantification that is, the use of statistics as a way of conveying risk to the audience. In the introduction, we discussed conflicting research findings regarding sex/gender differences in the incidence rate of Alzheimer's disease. Given this empirical uncertainty, the use of statistics by platforms directed at individuals unfamiliar with the nuances of clinical research can reveal, to a certain extent, the goals and orientations of such platforms. Specifically, we were interested in the use of statistics in positioning women as at-risk and in the related encouragement of certain behaviors and attitudes. Here, it is important to recognize the cultural impact of statistical information. Statistics are often portrayed, out of necessity or by design, without context. Ironically, it is this vagueness that allows for personalization and statistical panic (Woodward, 1999). Without mitigating information, it is much easier to emphasize someone's chance of becoming ill and diminish the usually larger probability of remaining healthy. Importantly, when examining which statistics are used and in which (lack of) context, we also take into consideration visual elements such as font, design, and placement, which can influence the uptake of the statistic as much as its literal meaning.

The women-oriented platforms we examined all report that roughly two thirds of Alzheimer's patients are women. The use of this statistic in and of itself is not inherently problematic—indeed coupled with caregiving statistics, in which women are also overrepresented, it is apparent that Alzheimer's has a disproportionate effect on women. However, our analysis shows that womenoriented online platforms almost universally highlight the "two thirds" or "almost 70 percent" statistic in an uncritical way. The issue of longevity, which could redirect the element of risk and statistical panic to age rather than sex/ gender, is rarely mentioned. Organizations that are not sex/gender specific are far less likely to mention this statistic in particular. If they do mention it, they either include the incidence qualifier or frame the statistic in the context of "impact" rather than risk. Thus, women-oriented platforms tend to position the two thirds statistic within a greater discourse on risk.

A typical example comes from the front page of the Women's Brain Health Initiative (WBHI) website. Set against the backdrop of the website's white, gray, and purple color scheme, a green box frames a large "70%." In a common motif across several of the women-oriented platforms examined, the outsized number is placed over smaller text clarifying the statistic. The visual semantics here are just as important as the statistic's actual meaning. The green background of the statistic serves to draw the

eye and the juxtaposition of font sizes communicates an initial shock or panic over the number, whether it be exceptionally high (as seen here) or low. Below the statement that "(70%) of Alzheimer's sufferers are women," there is a visual pun: "you can't ignore a number this big" (Women's Brain Health Initiative, n.d.). The pun is acknowledged but also reinforced—the number is not just shocking because it stands out from the rest of the text, but also because it signals a disproportionality. Particularly in the context of a charity organization, the word "ignore" introduces a moral element to the two thirds discourse.

In a second example from the front page of the Women's Alzheimer's Movement (WAM) website, the two thirds statistic is combined with a warning that "Every 65 seconds, a new brain develops Alzheimer's." This statement is overlaid on an image of mostly-young women standing with arms around each others' shoulders, laughing. In conjunction with the text, the image serves to illustrate that "new brain" could belong to any woman, in a way designed to be relatable and personalizing to the viewer. The youth of the women in the photo challenges the idea that Alzheimer's only affects the elderly, making the impact of the two thirds statistic much more immediate to a potentially young and female audience. Notably, below the statement that two thirds of Alzheimer's sufferers are women is a button (leading to a donation page) that states "help us find out why" (The Women's Alzheimer's Movement, n.d.-b). "Help us find out why" implies that there is little, if any, research explaining this statistic. This discourse relies on a compounding of uncertainty—that not only do women have some sort of inherent, immediate risk, but that there is (as of yet) no method of mitigating that risk. However, the same website also contains a prevention section with an array of advice on maintaining a healthy brain, discussed below.

A third example comes from the homepage of the Women and Alzheimer's website. An image of a woman walking her dogs on a beach is overlaid with the text "5.4" million Americans suffer from Alzheimer's disease," "4.0 million of them are women" (Women & Alzheimer's, n.d.-b). Again, the numbers are inflated relative to the size of the text, as if the numbers can almost speak for themselves. Quantification is employed here for affective impact. While paired with a very different image—the woman here faces away from the camera, but her white hair implies she is perhaps a bit older—it is still deliberately vague in a way that encourages viewers to identify with this woman. Underneath the image, the familiar two thirds statistic is provided in red text: "At age 65, a woman is two times as likely to develop Alzheimer's disease than a man. By age 75, she is three times as likely." Both of these examples encourage identification with this frightening statistic.

In all three examples, the most prominent statistics do not reflect the actual average chance of developing Alzheimer's for any individual woman. In line with Lawless et al.'s (2018) analysis, we found that the gender nonspecific platforms include incidence statistics more often. By foregrounding statistics regarding the sex/gender gap rather than actual incidence, and making this statistic personal and relatable, women's brain platforms position Alzheimer's disease as an urgent concern for the majority of women (if not *all* women). While centering the idea of Alzheimer's as a women's issue is understandable for gendered platforms, this affective maximization of perceived risk serves to induce statistical panic and thereby motivate women to engage in preventive behaviors recommended on these platforms.

## Risk Management

As counterbalance to this discourse of risk, many of the websites examined offer a discourse of risk management, mainly via prevention practices. However, as seen in the presentation of risk itself, this discourse is oftentimes heightened in women-oriented spaces. For example, the Alzheimer's Association's (a sex/gender nonspecific organization) prevention page emphasizes that "there are no clear-cut answers yet" and states "While research is not yet conclusive, certain lifestyle choices, such as physical activity and diet, may help support brain health and prevent Alzheimer's . . . " (The Alzheimer's Association, n.d.). Meanwhile, the front page of the WBHI advertises their blog series "Memory Morsels," which promises recipes and tips to "help keep your brain functioning the way you want." This text of this advertisement is overlaid on a posed stock photo, this time of a woman eating at what is presumably an expensive restaurant, as indexed by the blurred but clean and white décor, her attire, and the presence of wine glasses on the table (Women's Brain Health Initiative, n.d.). While the photo shares some qualities with the deliberately vague and therefore relatable photos examined above, this seems to draw on aspirational marketing (Dimofte et al., 2015). The woman in the photo is well dressed, thin, and white. While the text ostensibly addresses a health concern, the phrasing of the text paired with the photo pulls its semiotic cues from marketing—maintaining a healthy brain diet is "sold" to the viewer through an association with beauty and wealth. Furthermore, placement within the website is also significant here. In the example comparison, the WBHI places messages about prevention on the front page, whereas the Alzheimer's Associations' prevention page is several clicks deep into the website and is categorized under "Research and Progress."

In a similar fashion, the WAM website places their "tips & tools" link at the top of the front page, which links

directly to their "prevention" page. The prevention page does include in small print that "there is no definitive answer" to Alzheimer's prevention; however, this statement is dwarfed by the word "Prevention" in large purple print and several large, brightly colored icon photographs denoting articles that contain prevention advice. These articles include recipes, interviews, guest blogs, and science reports with titles that suggest a relatively large control over our brain health, often in a handy "listicle" format, such as: "5 Lifestyle Changes That Keep Your Brain Sharp at Any Age" and "The 6 Key Things to Do to Outsmart Alzheimer's" (The Women's Alzheimer's Movement, n.d.-a). Of the 43 posts on the prevention page, 22 have to do with diet and/or exercise. The rest are scattered over meditation, staying socially engaged, and other individualized behaviors. The regular use of imperative language in these titles (e.g., "Early Alzheimer's Prevention: 4 Things You Should Do Now") positions preventive behavior not merely as promising and desirable, but as an obligatory practice.

Overall, prevention discourses, while not universal, appear more frequently and with more prominence on women-oriented websites. While a variety of lifestyle concerns are discussed, there is an overwhelming emphasis on diet and exercise. Coupled with the "marketing" vernacular employed by many of these websites, as well as larger cultural discourses that encourage women to stay slim, this emphasis is both expected and concerning, as it feeds on and reinforces gender normativity. Furthermore, the explicit suggestion that such lifestyle adjustments can prevent cognitive decline glosses over the impact of nonmodifiable risk factors, as well as structural and individual barriers to lifestyle optimization.

## Risk Dispersion

The discourse of extensive prevention practices is underwritten by one of risk dispersion. This wide net of preventive measures is drawn from the diverse efforts to uncover the underlying causes of Alzheimer's and dementia. Conditions or lifestyle factors that have been researched in connection to Alzheimer's, regardless of how tentative or speculative that research may be, are reframed as risk factors. Risk is thereby dispersed horizontally, across factors that an individual may or may not have control over. While many of these websites acknowledge important advances in genetic research, prevention discourse focuses on risk factors that can ostensibly be mitigated, that is, lifestyle factors. Take, for example, a post under the "tips & tools" section of the WAM website called "Shining a Light on Vitamin D (2018)":

New research suggests that having an adequate level of vitamin D in older age could possibly slow down cognitive

decline and contribute to reducing the risk for dementia, especially Alzheimer's disease.

A recent study of 916 cognitively healthy, older adults that were followed for 12 years found participants with deficient levels of vitamin D exhibited a faster rate of cognitive (memory and thinking) decline and had a three-fold increased risk of Alzheimer's.

While sharing this information is not in and of itself problematic, it is immediately followed by the heading "Need to Increase your level of the 'Sunshine Vitamin'?" and a list of tips "to bolster your levels of vitamin D." New research, completely decontextualized, is thus taken as sufficient motivation to encourage lifestyle changes and translated into specific recommendations: readers are encouraged to get enough sun, make dietary changes, and even consult their physicians about their vitamin D levels.

In a similar vein, the "knowledge" section of the WBHI website reports on single studies that have found some association between brain health and lifestyle factors. These are reported under the rubric of "everyday information" rather than the adjacent rubric "scientific information," thus suggesting that the audience can immediately apply the outcomes of these studies to their daily routines. Paired with recipes and diet recommendations, exploratory research is thus reframed as an ever-expanding list of risk factors that require immediate preventive measures. We argue that this discourse of risk dispersion, linked to that of risk management, indexes a moral component of health, as each newly uncovered association is translated into desirable or even imperative behavior—even before research findings are replicated and confirmed. When considering Alzheimer's, a disease in which the underlying mechanisms are still not well understood, one might imagine a lessening of the moral duty to stay healthy, or a submission to the whims of genetics. However, there seems instead to be an intensification and dispersal of risk.

Because prevention is not certain, efforts must be doubled. In keeping with the wider contemporary emphasis on medical self-management and informed patienthood, the audience is encouraged to keep up with the ongoing scientific quest for new candidate mechanisms and to apply this knowledge to themselves in a competent way. Sometimes this is done in the form of one-size-fits-allwomen advice, at other times the audience is encouraged to craft a personalized approach for themselves from the available tips. For example, in an article titled "Assessing your Alzheimer's Risk" on the WAM website, a checklist of risk factors is provided to "[give] you a clue where to start making changes to reduce your risk for developing this terrible disease." The article encourages the reader "determine the best brain health recipe for you" because everyone's risk factors are different (Kosik, 2017). Such checklists, as well as quizzes and tests, are used more frequently to challenge women to assess their risk or test their general knowledge of the disease. Most tellingly, in a quiz titled "what's your brain age?" in the second edition of WBHI's online magazine Mind over Matter, the final statement to be scored reads "I'm ready to prevent Alzheimer's and am willing to do whatever it takes" (What's your brain age?, n.d.). In this (perhaps extreme) example, one's health is defined not merely through preventive behavior itself but also, partially, through the correct attitude toward preventive behavior, sending a strong moral message. In contrast, sex/gender nonspecific organizations such as the Alzheimer's Association and National Institute on Aging (NIA) list signs and symptoms, but encourage far less active engagement.

Furthermore, risk is dispersed not just horizontally across different risk factors but also temporally to those who may be decades away from first showing symptoms. Whereas some messages stress that it is never too late to start working on brain health, others caution that it is never too early. The statement that "researchers now believe that Alzheimer's disease begins to develop in the brain up to 20 years before the first symptoms occur . . . " (Alzheimer's disease, n.d.) is reiterated across almost all of the gender-specific websites considered. While this information is present on gender nonspecific websites, it is usually less prominent and expressed more vaguely and neutrally as "changes" to the brain, and the number of years is not specified. In contrast, starting prevention early is suggested more strongly on the women-oriented websites.

Many women-oriented websites consistently feature images of young women, which in addition to making risk relevant to potentially younger audiences, reinforces the idea that prevention must be a lifelong effort. The WBHI even recently launched a campaign called "Millennial Minds." Although many "millennials" are now well into their 30s, the image accompanying this campaign indexes a form of youth more strongly associated with teenagers: a woman is depicted laying on the floor, staring up at her smartphone, surrounded by books and open magazines (Women's Brain Health Initiative, n.d.). There is the explicit suggestion that women can have full control over their brain health, but only through a constant and lifelong engagement in risk management. While this may appear to conflict with messaging that stresses the need for more clinical research, risk dispersion reconciles these by incorporating constant engagement with new research as necessary for staying up-to-date on one's prevention practices.

## Gendering of Risk

Dispersed risk not only occurs to a greater extent in women-specific online spaces, but is also communicated

in a gendered way. It is particularly demonstrative to look at one of the few non-sex/gender-specific websites that does acknowledge the disproportionate impact that Alzheimer's has on women, the Cure Alzheimer's Fund. Importantly, the information relevant to women is cordoned off to a specific page within a larger section of the website labeled "the disease." Most of the pages within "the disease" section consist of a large photo header followed by two short paragraphs, with more detailed paragraphs and images below.

However, while still within the "disease" section, the "Women & Alzheimer's" page initially follows the same format—large photo header, two short paragraphs—before launching into a series of statistics (Women & Alzheimer's, n.d.-a). Again we are confronted with quantification, with the shocking nature of the numbers prioritized over the clarifying text. This is the only page under "the disease" section that deviates so significantly from the others. Even a page in the same section labeled "Stats & Costs, n.d." does not rely on quantification as heavily as the "Women & Alzheimer's" page does.

The Cure Alzheimer's Fund website's simple design and limited color palette communicates associations with "hard" science, eschewing the more emotional communication styles of other websites, both general and women oriented. This makes the dire tone of the "Women & Alzheimer's" page all the more striking. The page is a long list of statistics, ending with a "0" as the number of women who have survived Alzheimer's. In contrast to the rather large numbers at the top of the page, a single "0" is stark and emphasizes the bleak, overwhelmed tone of the page. While obviously meant to inspire individuals, particularly women, to donate, it ultimately uses statistics to communicate fear. Furthermore, the Cure Alzheimer's Fund also owns a women-oriented website, womenandalzheimers.org. This orientation toward statistical panic carries over from the parent site, as discussed in the quantification section above.

Apart from heightened risk discourse, our analysis reveals that websites and online spaces specifically directed at women often attempt to make information relevant to women in a "day to day" or "basic" sense. For example, My Brain is a women-oriented website owned by the Alzheimer's Association, and the tone of the site is strikingly different from its parent organization. Indeed the very name of it indicates a strategic personalization. Their "about the movement" page specifically makes the point that "At 3 pounds, your brain weighs less than your purse . . ." The text is reiterated in a purple "infographic," utilizing the curlicue and italicized fonts present throughout the website (About the movement, n.d.). The font and comparison to a feminine accessory serve to aim this message directly at women, thereby enabling the "nichemarketing" of statistical panic throughout the website. In

addition, it reinforces hegemonic femininity, specifically expectations of self-care and optimization.

This feminization can also be seen in the WBHI's creation of a "magazine." This again brings Alzheimer's advocacy from the realm of the medical into discourses of self-optimization. Moreover, these magazines feature glossy, posed covers and have small headlines mimicking other women's magazines. The women featured on the covers are typically well dressed and styled, in a way that walks the line of relatable yet aspirational (Findlay, 2019). They contain quizzes such as "what's your brain age?" and attempt an endearing "hey girlfriend."

Thus, the discourses of risk, prevention, and risk dispersion are not only heightened in women-specific spaces, but are specifically packaged in "feminine" aesthetics. This feminine packaging asserts that this is a risk specific to you as a woman and serves to personalize and direct the uptake of risk statistics. By using the existing cultural script of a women's magazine, brain health is grouped together with the same expectations of self-management and optimization as weight loss and maintaining beauty standards. Personalization of risk thus has the potential to be particularly effective because it is framed in a familiar fashion. Maintaining brain health is simply added on to the list of self-optimization behaviors advocated by the magazines that "Mind over Matter" styles itself after, pushing it further into the realm of personal responsibility. A serious health concern is thus transmuted into something that can and must, morally, be managed on an individual level.

#### **Discussion**

In this study, we have analyzed how the risk of Alzheimer's disease and the responsibility to prevent it are constructed on online women's brain health platforms. We have explored four overarching themes that emerged from our multimodal analysis: quantification of risk, risk management, risk dispersion, and the gendering of risk. We also compared general online platforms to websites specifically aimed at women, allowing us to comment on specific trends in women-oriented campaigns. Earlier studies of representations of Alzheimer's disease identified a dual discourse that represents it as a catastrophic threat as well as a fate that individuals can and must prevent (e.g., Lawless et al., 2018; Peel, 2014). A similar dual discourse was identified in the present analysis, whereby both the insistence on risk and the individualization of responsibility appeared to be intensified on women-oriented platforms. Our analysis thereby confirms and extends previous work on the online representation of dementia, as well as previous work on women's health discourses.

With regard to the construction of risk, we found that this was mainly communicated through quantification, that is, the use of statistical information as a rhetorical device to maximize the affective experience of personal risk (cf. Lawless et al., 2018). We found that this strategy was characterized by the selective presentation of statistical information (e.g., pervasive repetition of the "two thirds" statistic combined with a scarcity of information regarding actual lifetime risk), as well as a striking visual pattern whereby large numbers overwhelm any explanatory text. This ubiquitous use of big numbers (big in a literal and figurative sense) positions women as a high-risk group for whom it is crucial to engage in preventive measures, as a moral duty to both themselves and society as a whole (Ayo, 2012). However, Woodward (1999) has suggested that such bombardment with threatening statistics can be counterproductive, as it may produce a state of boredom or cynicism rather than the "statistical panic" that can motivate behavioral change. To reach maximum impact, campaigners must therefore ensure that the audience experiences statistical risk as personal destiny. We suggest that the gendering of risk, a major theme that emerged in our analysis, serves to "niche market" and thereby personalize quantified risk. Indeed, the quantification of risk was more apparent on women-oriented platforms than on the general websites that we examined, supporting our assertion that the combination of quantification and gendering represents a specific strategy. In the women-oriented campaigns that we examined, gendering figured in multiple ways: besides the focus on the sex/gender disparity among Alzheimer's patients and the framing of Alzheimer's disease as a women's issue, we found recurrent use of visual and textual styles that appeal to normative femininity (curly italics, soft colors, glossy magazines) as well as an emphasis on preventive behaviors that are traditionally associated with womanhood (dieting, exercising, preserving youthfulness). Even the conspicuous reliance on quantification itself could be taken as a form of gendering, as it appears to rely on the stereotypical assumption that women are particularly susceptible to this form of affective manipulation.<sup>3</sup>

Besides risk quantification and the gendering of risk, we identified risk management and risk dispersion as major recurrent themes. The platforms we examined strongly suggest that women can escape looming cognitive decline if they adopt the correct attitude and lifestyle. This fits with a conceptualization of risk that holds the individual responsible to avoid ever-present risk factors rather than, for example, collective efforts to remove risk factors from the environment (Crawford, 2006; Ogden, 1995). This neoliberal logic, which glosses over structural social ills and centers on individuals as self-contained and self-regulating consumers, requires individuals to invest personal resources in the constant avoidance of

health hazards and optimization of resilience (Ayo, 2012). Furthermore, it requires patients and non-patients alike to stay informed of expert knowledge to adjust their selfcare lifestyle accordingly. We have shown that womenoriented platforms propagate this consumerist discourse in several ways, including checklists and quizzes and minute updates of the latest and sometimes highly preliminary scientific studies, the results of which are often prematurely translated into practical behavioral advice. Furthermore, the net is cast wide by the suggestion that it is never too late, but certainly never too early to engage in preventive behavior—thus, risk and risk management are not just dispersed across numerous risk factors but also across time. Again, these themes appeared to be intensified on women's health platforms compared with general Alzheimer's websites and it is reasonable to argue that this also constitutes a form of gendering, as it reflects and constructs the stereotypical positioning of women as conscientious health consumers. On the surface, the platforms that we examined appear to benefit and empower women, allowing them to protect and improve their own health while scientists continue to search for answers. Indeed, all of the websites also promote further scientific research through fundraising and other means. We by no means intend to diminish the research and advocacy work done by the organizations and individuals behind these initiatives. Alzheimer's disease and women's health more generally are both in dire need of greater understanding, and online platforms can clearly play a significant role in raising awareness and supporting research. However, our analysis showed that these websites also construct an identity for women that is characterized by a moral obligation to engage in preventive behavior as well as an alignment with normative femininity, under the untenable promise that compliance leads to healthy aging. As such, they place an unrealistic pressure on individual women to reduce health disparities and prevent cognitive decline despite (or, as we suggested earlier, given) the scientific uncertainty regarding the nature and possible management of Alzheimer's disease and the reasons behind the sex/gender gap. Indeed, we find a certain irony in the fact that women are exhorted to manage their health risks on the same platforms that address the fact that these risks are poorly understood by medical professionals due to a gender bias in medical research.

We see the individualization and gendering of this burden as ethically problematic, like others before us (e.g., Broer & Pickersgill, 2015; Lawless et al., 2018; Pitts-Taylor, 2010; Thornton, 2011). First of all, the construction of Alzheimer's disease as entirely or largely preventable through self-care practices belies the limitations of current scientific understanding of the condition and the complexity of risk. Lifestyle factors may be associated with risk of Alzheimer's on a population level, but

this does not mean that management of these factors is guaranteed to eliminate or even significantly lower a given individual's risk. Furthermore, the one-size-fits-all appearance of most of the advice on these websites discounts the ways in which differences and inequalities between women restrain the capital required for making beneficial lifestyle choices (e.g., money for healthy food, time for exercising, access to education and health care) and avoiding certain risk factors (e.g., stress, air pollution, social isolation, comorbid conditions). This may lead to the stigmatization of women who do not invest in a preventive lifestyle, regardless of the reasons that keep them from doing so. At worst, the logic of prevention through self-care leads to the conclusion that developing Alzheimer's is a personal failure. Finally, the focus on individual practices may pose a barrier against the development of collective and systemic protective measures against the social determinants of brain health.

Our analysis shows striking parallels with other women's health campaigns. For example, the neoliberal, individual-oriented, and gender-normative motifs that we identified have also been highlighted by analyses of breast cancer and heart disease discourses (e.g., Clark et al., 2018; Gonsalves et al., 2016; Hesse-Biber et al., 2018; Jain, 2007; King, 2006; Sulik, 2011). Thus, women's brain health campaigns partake in a wider discourse that positions women as responsible for managing their health through individual lifestyle "choices" that are closely aligned with middle-to-upper-class, hegemonic femininity. In addition to the critiques already mentioned above, it has been argued that this discourse not only tightens the normative association between women and care but also heightens the medicalization and public scrutiny of women's bodies (e.g., Riley et al., 2018).

There is one point of departure from other women's health discourses, however, which was beyond the scope of our central analysis but which we do not want to leave unaddressed. Analyses of other women's health campaigns have widely commented on the whiteness of the assumed (and visually represented) audience (e.g., Gibson et al., 2015; Gonsalves et al., 2016). In contrast, our analysis of women's brain health platforms showed a strong visual representation of racial and ethnic diversity, often in prominently placed group pictures. Such representation is important in light of racial and ethnic health disparities. For example, data from the United States show that dementia risk is twice as high for African Americans compared with Whites (Mayeda et al., 2016). However, the platforms we examined scarcely mention this type of research. Although we cannot say with certainty how audiences may interpret these images, we have suggested elsewhere that this visual representation of diversity in the absence of further information on racial and ethnic health disparities may precisely function to

erase the importance of racial and ethnic differences, by implying that women of all colors are united under the shared threat of Alzheimer's disease (Kleinherenbrink & Mohr, 2020). In other words, rather than calling attention to the intersections of various axes of inequality, these images may precisely serve to elevate womanhood as a universal and overriding determinant of brain health and is a topic worthy of further study.

There are important limitations to our study. First, it offers no insight into how these discourses are taken up, integrated, or ignored by internet users. Individuals may, of course, resist hegemonic risk discourses (Fage-Butler, 2017). For example, they may reject expert advice and make up their own minds through the very individualizing impulse that these discourses encourage (Versteeg et al., 2018). In addition, the reflection and construction of hegemonic femininity in health campaigns can exclude or alienate women who do not align themselves with traditional notions of womanhood—a critique that has been particularly well developed with regard to breast cancer campaigns (e.g., Jain, 2007). Future research may therefore investigate how women's brain health campaigns are actually received by the intended audience. Furthermore, this study is not intended as a comprehensive analysis of online dementia discourse. Our sample is of limited scope and represents a "snapshot" of websites and therefore discourse that will evolve and change over time. The sample is limited to English-language sources and therefore sheds light on some, but not all, online health communication about women and Alzheimer's disease. Our research is therefore not a definitive statement on this particular aspect of online women's health discourse, but rather a critique intended to nudge its development in a positive direction. Using the insights from our analysis, campaigners may reconsider their strategies in light of the ethical implications that we have brought up. These reconsiderations may include, in our view, more nuanced information on the risk of developing Alzheimer's disease, fairer representations of individuals' control over the various determinants of their health, and less normative representations of womanhood.

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#### **ORCID iD**

Victoria Mohr (D) https://orcid.org/0000-0001-9252-4407

#### **Notes**

- Distinguishing the terms "sex" and "gender" is often recommended as best practice in recent women's health literature (e.g., Madsen et al., 2017). Against this trend, we prefer the composite term "sex/gender" to highlight the entanglement of the biological and the sociocultural, believing that differences between men and women are rarely the effect of a single domain, particularly in health and illness. The fundamental interaction between the material and the experiential is discussed in more detail by Springer et al. (2012). We will occasionally use the terms "sex" and "gender," however, when the emphasis is clearly on one side of the purported nature—nurture divide (e.g., "gendered norms").
- As comparable (sub)site traffic statistics are impossible to gain either from the websites themselves or for example, Alexa.com, we have thus relied on different criteria in the selection of sites for analysis.
- 3. We thank one of our anonymous reviewers for this insight.

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#### **Author Biographies**

**Victoria Mohr** is a research masters student at the Department of Culture Studies, Tilburg University, The Netherlands. Her research focuses on discourses of the body and technology.

**Annelies Kleinherenbrink** is a postdoctoral researcher at the Department of Culture Studies, Tilburg University, The Netherlands. Her research focuses on gender, discourses of health and illness, and critical approaches to neuroscientific research.

**Piia Varis** is an associate professor at the Department of Culture Studies, Tilburg University, The Netherlands. Her research focuses on digital culture and communication.