THE POWER OF MESSAGING: AN EXAMINATION OF

A RIGHTS-BASED APPROACH

TO DEMENTIA

by

Brenda Fagan, B.S.

A thesis submitted to the Graduate Council of
Texas State University in partial fulfillment
of the requirements for the degree of
Master of Science
with a Major in Dementia and Aging Studies
December 2021

Committee Members:

Kyong H. Chee, Chair

David Dietrich

Rebecca Deason

FAIR USE AND AUTHOR'S PERMISSION STATEMENT

Fair Use

Duplication Permission

DEDICATION

I dedicate this work to every unique individual living with dementia, their families, friends, and communities. May you know you are valued and that your voice matters.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

Abbreviation	Description
ADI	Alzheimer's Disease International
ATLAS.ti	Archive for Technology, Lifeworld and Everyday Language.text interpretation
GAPD	Global Action Plan on the public health response to Dementia
PLWD	Person/s Living with Dementia
SPSS	Statistical Package for the Social Sciences
WHO	World Health Organization

I. INTRODUCTION

The experience of living with dementia is socially constructed from attitudes and beliefs about dementia (Stites, et al., 2018) and how those beliefs are embodied and enacted in society. Societal values dictate how attitudes and beliefs are enacted in social context through interaction between individuals, individuals and organizations, and individuals and society. The values of a society, organization, or nation are communicated as messages through symbols. For example, the United States Declaration of Independence states "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness," (U.S. Constitution, pmbl). This message conveys the ideological attitudes, beliefs, and values of the United States by using words which symbolize a nation that supports the rights of individuals including those living with dementia. Currently there are 6 million people in the United States living with dementia (Alzheimer's Association, 2020) with projected estimates reaching over 13.8 million by 2050 (Hebert, et al., 2013). Hence, to reflect the values of the United States, messages about dementia should be inclusive and support the rights of the millions of people in the nation who are living with dementia.

In 2015, there were 47 million people worldwide (or about 5% of the world's older adult population) living with dementia (WHO, 2017). That number is expected to exceed 135 million by 2050 (WHO, 2017). In response to the growing global need to address the increasing prevalence of dementia and the associated impact on individuals and society, the World Health Organization (WHO) developed the Global action plan on the public health response to dementia (GAPD). The GAPD's approach is consistent with

the aforementioned values of the United States that emphasize the rights of individuals with the plan intending to create "a world in which dementia is prevented and people with dementia and their care partners live well and receive the care and support they need to fulfill their potential with dignity, respect, autonomy and equality," (WHO, 2017). One hundred ninety-four nations, one of which is the United States, signed the GAPD indicating their commitment to the global plan and a rights-based approach that highlights the principle of "human rights of people with dementia," (WHO, 2017, p 5). Consistent with the United States Declaration of Independence, a rights-based approach to dementia would support the dignity, respect, autonomy, and equality of those living with dementia which includes their rights of self-determination, independence, participation, and inclusion (CMI CHR. Michelsen Institute, n.d.; Scottish Human Rights Commission, n.d.). These qualities are at the core of a person-focused approach to dementia which challenges the historical disease-focused approach (Butchard & Kinderman, 2019; Mann, 2020). Although there has been a shift over the past 30 years toward a more person-focused approach, some organizations continue to approach dementia care and research from a disease perspective which focuses on cure and prevention (The Alzheimer's Association, 2021.a).

  The global community is calling for a rights-based approach to dementia that balances disease and person-focused perspectives (Vernooij-Dassen, 2021; WHO, World Health Organization, 2017). To create a more balanced approach, attention must be directed toward the attitudes and beliefs about dementia that contribute to an unbalanced approach which includes person-centeredness and dementia stigma (e.g., Kontos, et al., 2020; Nguyen & Li, 2020). There is an abundance of literature that supports a person-

centered approach to dementia care and the value of a person versus disease-focused approach to decrease stigma (Benbow & Jolley, 2012; O'Connor, et al., 2018). Stigma literature from the voices of persons living with dementia (PLWD) has identified the most prevalent attitudes that isolate PLWD from society including specific language and messaging (Butchard & Kinderman, 2019; Reed, et al., 2017). There are, however, no studies known to this author that examine national dementia messaging from representative dementia organizations to determine which approach is being used. Messaging for this study is defined as electronic communication through text and images that are disseminated via website homepages. Therefore, the main purpose of this study is to examine and compare public messaging about dementia in the United States with dementia messaging in other countries.

To address the gap in the literature, I conducted an ethnographic content analysis of national association website homepage messages for countries purposively sampled among nations that agree with and have signed the GAPD. The following research questions were posed: What message is being conveyed to persons living with dementia, their care partners, and the public about dementia in the United States? Who is the intended receiver of the message? Does the messaging align with the global dementia care plan for a rights-based approach to dementia? How does dementia messaging in the United States compare to that in other countries? Answers to these questions will provide empirical evidence about what is being communicated about dementia and whether national organization messaging supports a balanced rights-based approach which includes dignity, respect, autonomy, and equality for unique persons living with dementia.

II. LITERATURE REVIEW

The predominant approach to dementia has been disease focused and based in a biomedical model for the past 40 years (Ballenger, 2017). There is, however, growing acknowledgement in medicine that this approach is not adequate. To address the complex needs in the context of society: "We need to foster attitudes, values, and communication skills that focus on illness, not just disease, to prepare ourselves for the challenges ahead," (Green, et al., 2002, p. 143). The biomedical model focuses on the "disease of dementia" and is often used in conjunction with hyperbolic language and portrayals of dementia in a predominantly negative light, most notably through beliefs in loss of one's sense of self and the ability to self-manage (Reed, et al., 2017). Messaging about dementia as a tragedy isolates PLWD and perpetuates dementia beliefs that reinforce stereotypes and stigma (Mitchell, et al., 2013; Reed, et al., 2017).

The personhood and citizenship movements have been gaining traction over the past 25 years and have shed light on the need to not only prevent and cure dementia but to invest in the care, inclusion and social justice concerns for persons living with dementia (WHO, 2017). The person-centered approach has grown out of Tom Kitwood's seminal work on personhood (Kitwood & Bredin, 1992) which has given rise to several movements and other approaches to dementia including embodied selfhood (Kontos & Martin, 2013) and citizenship (Bartlett & O'Connor, 2007). Personhood is social-psychological approach to caring for PLWD that focuses on interdependence and the well-being of individuals with dementia and their care partners (Kitwood, 1992). Kitwood's seminal work changed the way dementia care is provided and included the concept of malicious social psychology where care partners inadvertently provide

harmful care not because of a lack of caring, but because of a lack of insight about dementia and the unique individual living with it (1992). The social environment influences the lived experience of dementia through the interactions between individuals and the cultural context in which the interaction takes place. The influence of messaging received about dementia shapes these interactions and the embodied selfhood of PLWD.

Embodied selfhood is the act of engaging with others using pre-reflexive body movements, those that operate below the threshold of cognitive thought (Kontos, 2004), to express agency and the unique self, such as making a hand gesture or reaching to adjust a necklace. Through embodied selfhood, PLWD express their personhood as a unique individual acting on their own behalf in ways that do not rely on traditional ways of expressing cognitive ability (Kontos, 2004). The citizenship approach furthers the concept of embodied selfhood and highlights the rights of individuals living with dementia as equal citizens who deserve respect and opportunities to contribute to their community (Kontos, et al., 2017). Citizenship is grounded in a rights-based philosophy and presented by Kontos and colleagues as a social justice issue (2017).

Considering the lived experience of persons with dementia was not the focus of dementia advocacy prior to recent years. The predominant way of thinking about dementia was from a crisis prevention standpoint. Messaging about dementia as a crisis started around the late 70's (Ballenger, 2017) and shortly after that in 1980, the Alzheimer's Association was created in the United States (The Alzheimer's Association, 2021.b). The vision of the Alzheimer's Association is "A world without Alzheimer's and all other dementia®," (The Alzheimer's Association, 2021.b). Despite billions of dollars and 4 decades of research, the number of people living with dementia continues to

increase, and we are no closer to a cure (WHO, 2017). The primary messaging used in the 1980's to secure funding for research was based on the present and historical vision of the Alzheimer's Association to eradicate the disease through biomedical research efforts (The Alzheimer's Association, 2021.b).

In absence of a cure, researchers and advocates for people living with dementia have shifted their focus to identifying ways to live better with dementia and turning their attention to well-being, quality of life, early diagnosis, and prevention (Shah, et.al., 2016). This new focus has also shifted attention solely from the disease or biomedical approach to a person-centered psychosocial approach (Vernooij-Dassen, et al., 2021) or what has also been called a biopsychosocial approach (Spector & Orrell, 2010). Whereas early diagnosis and prevention may rely on biomedical investigations of the disease, person-centered approaches stem from the concept of personhood and the value of putting the person at the center of care, service provision and policy making. Messages that use language and values inclusive of the person, not just the disease or condition, are considered person-centered and can influence attitudes and beliefs about dementia. For example, use of the term "person living with dementia" versus "dementia patient" can create a foundational mindset that places power with the person rather than the disease, and positions the person at the center where further person empowering attitudes can be built.

Dementia messaging through mainstream media (Gerritsen, et al., 2018; Peel, 2014) and online forums (Mehta et al., 2020) contribute to the construction of beliefs about dementia. Dementia stigma and stereotyping are barriers to promoting social justice and inclusion for PLWD (Mukadam & Livingston, 2012). There are three aspects that

compromise stigma: stereotypes, prejudice, and discrimination (Benbow & Jolley, 2012). The way PLWD see themselves and are seen by others can lead to self and social acceptability or disconnection and social isolation. Dementia stereotyping stems from depictions of PLWD at end stage when the person is most impacted by symptoms of the condition. People can live with dementia for many years without these challenging symptoms, yet the stereotype remains. Prejudice and discrimination stem from the stereotypes to create stigma. One way to decrease stigma and shift beliefs to a more positive perspective is through the messaging being used on dementia websites. The messages that organizations send whether intentionally or inadvertently may change what healthcare providers, care partners, PLWD, and the public believe about dementia and people living with the diagnosis. Websites for national dementia organizations may be the first-place people are referred to for resources about dementia and potentially one of the first places they encounter dementia messaging.

There is no question that the needs of PLWD and their care partners must be approached as a societal or global issue. The individual and global cost is too high to ignore given the trend in the number of PLWD in the United States and in the world. However, the ways in which the world has addressed these issues so far and what is believed to be the appropriate approach moving forward is somewhat debatable. Even so, there is a predominant message from PLWD (Calvert, et al., 2020) and their advocates, that clearly points to a more person-focused approach (WHO, 2017; Mann, 2020). The first area of contention for increasing attention to the person living with dementia and moving toward a more balanced approach is addressing the tragedy discourse (Reed, et al., 2017) such as the phrase, "the living death of Alzheimer's," (Revoir, 2011).

Tragic Disease Messaging

Burke writes that by framing dementia as a disaster we are communicating that dementia is "an unmanageable and unsustainable burden intrinsic to the nature of the condition," (Burke, 2017, p. 8). This messaging, Burke argues, limits the possibility of thinking about living with dementia any other way. Although disaster and tragedy messaging may be beneficial for raising funds for research, the implications for those who are living with dementia can prove detrimental as Ballenger points out (2017). Reed and colleagues call for ending the tragedy discourse of dementia, calling it "an ethical imperative," (Reed, et al., 2017). The tragedy discourse also feeds the stigma around dementia creating an environment of further isolation for PLWD and their care partners. Mitchell, Dupuis, Miller, and Kontos have done extensive research in challenging stigma by highlighting the strengths and capabilities of PLWD at all stages of disease progression (Kontos, et al., 2017; Mitchell, et al., 2013).

Nguyen and Li conducted a systematic review of global stigma and dementia and discovered the need for public and self-stigma dementia research that is sensitive to culture and "mass media campaigns to reconstruct public perception of dementia," (2020, p.177). Additionally, Gerritsen and colleagues explore the implications of "perceptions and portrayals" of dementia and the impact for dementia-friendly communities (2018). In the context of national strategies, the authors argue for actions to decrease stigma through interaction between PLWD and the public within communities (2018). Avoiding messaging that may increase stigma and further isolation for PLWD should be a priority which can be accomplished with a balance of positive person-focused messaging.

Positive Person Messaging

A positive person approach to dementia entails shifting the focus from what is not working to what is and gaining knowledge about dementia from the lived experience versus solely from the observation of PLWD. There is a moderate amount of literature written by PLWD and in collaboration as co-researchers (Malterud & Elvbakken, 2020). The majority of PLWD in this population have younger onset dementia and have been voicing their experiences and changing beliefs about what PLWD can do (Oliver, et al., 2020). Although this population may experience dementia differently than what is currently considered typical for PLWD, there is a good chance what is considered typical will change as people are being diagnosed earlier in the progression and at an earlier stage in life. Stories from PLWD combined with dementia friendly initiatives (Hebert & Scales, 2019; Lin & Lewis, 2015) that aim to create inclusive, supportive, and empowering environments for PLWD, have helped shape the goals and priorities at a national level and for the GAPD (Cahill, 2020). Community partnerships between businesses, cities and dementia advocates form the foundation of dementia friendly initiatives that are specific to the needs of each community and provide opportunities for the public to learn about dementia and engage with PLWD. Dementia friendly initiatives in the form of surveys, community observations and interviews have been implemented around the globe to improve environmental design, dementia education, awareness, and inclusion of PLWD in church communities, urban and rural spaces, and in collaboration with local governments and state organizations (Hebert & Scales, 2019).

Dementia Knowledge and Beliefs

Creating new beliefs and shifting old ones about dementia requires an understanding of where people gain knowledge about dementia. Shakespeare, Zeilig and Mittler argue that the dementia community would be better served if they framed dementia as a disability and looked to the disability community for ways to gain social justice and equal rights (2019). This approach has both merit and complications like the rights-based approach of the GAPD, especially for Western cultures, "where outdated legislation exists on legal capacity; where substitute rather than supportive models of decision-making are in evidence," (Cahill, 2020, p. 199). People may want to support PLWD, but a cultural shift at all levels is required and needs to be supported at the local and national levels.

Dementia friendly communities and dementia cafes offer opportunities for dementia education and intergenerational activities in local communities where people that do not have dementia mingle with PLWD in a supportive environment. Herbert and Scales discuss the use of person-centered language and attitudes that support collaboration and inclusion in their review of dementia friendly initiatives (2019). People learn about dementia through these communal interactions and, as Hebert and colleagues point out, improving the comfort community members have interacting with PLWD can decrease fear of dementia and "foster personhood-based knowledge," (2020). Cheston, Hancock, and White (2019) examined whether more interaction with PLWD would change attitudes about dementia and found that although more interaction is positively associated with person-centered beliefs and attitudes, it is likely to increase worries about developing dementia.

Web of Information

Personal interaction is one way to gain knowledge about dementia, but the Internet and the associated messaging on the web is another prominent place where people may learn about dementia especially in high income countries like the United States where Internet use is increasingly a part of everyday life. Mehta and associates analyzed Twitter and health forum posts where PLWD and care partners shared information but did not specifically investigate messaging coming from dementia-focused organizations (2020).

Including the voice of PLWD and their care partners as contributors to dementia messaging on the internet, Bosco and colleagues explored the role of PLWD as agents with the power to influence attitudes and beliefs about dementia from a first-person perspective (2018). Their results indicate that perceptions of dementia influenced by culture and over time have impacted the way dementia is currently represented, which is, however, not necessarily an accurate representation of modern dementia or PLWD.

Among the few studies that have explored dementia messaging on the Internet, none known to this author have focused on messaging contained in dementia association websites including the largest dementia association in the United States, the Alzheimer's Association. At the time it was established in 1980, the Alzheimer's Association was primarily concerned with supporting families of people living with Alzheimer's and related dementias and to advocate for dementia research which included political activism to acquire federal funding. Over time, the name and the mission of the Alzheimer's Association has shifted from Alzheimer's Disease and Related Disorders Association created to provide care, support, and dementia research, to a primary focus

on fund raising for Alzheimer's research. The Alzheimer's Association has a strong internet presence with the potential to shift beliefs and attitudes about dementia based the broad reach and strong reputation it has nationally and globally.

To address the dearth of information on dementia messaging, this study examines the focus, attitude and intended receiver of messaging on national dementia website homepages and determines if they are aligned with the rights-based approach as indicated in the GAPD.

III. THEORECTICAL FRAMEWORK

Social constructionism, as explained by Berger and Luckmann, posits that experience is shaped and transformed through social interaction and the meaning individuals derive from those interactions (1966). They argue that reality is created through shared thoughts and actions or attitudes, beliefs, and behaviors within a society. This shared reality may create a false belief that there is an external concrete reality within which all individuals live. If we all believe the same thing, it must be real and true. For example, dementia is a tragic disease that renders people helpless and unable to contribute to their own well-being. Although this may be real and true for some people, it is not for all. Some PLWD and their care partners have found positive experiences living with dementia (Wolverson, et al., 2016) and found ways to include PLWD in their own decision making into late stages of the condition (Dewing, 2007; Kontos, et al., 2017). The experience of living with dementia is constructed through messages conveyed through social interactions during the enactment of attitudes and beliefs. Interactions are not confined to physical interactions only; they also occur through interaction with text and images via the Internet.

Harding and Palfrey argue that dementia is a social construction where society positions people living with dementia outside social norms where they are ostracized, socially isolated, and labeled as diseased (1997). The power of this influence through messaging can shape attitudes and beliefs about dementia which are enacted through embodied engagement between individuals and between individuals and Internet content. The power lies with the framer of the messaging.

People in power may frame messaging about social phenomena in ways that can

create imbalance between those that have the power to spread information through media access to broad audiences and those who do not. This imbalance may also create false beliefs that can shape reality. Reality is framed by whomever is conveying the information. Goffman explains framing as a way of organizing, labeling and infusing meaning into the everyday world (1974). By taking a certain perspective, a message can convey a very specific meaning or reality. If a different perspective were taken to share the same information, attitudes and beliefs about the information could be different. The perspective or framing of the message can influence the meaning of the message for the receiver. Snow and colleagues used frame alignment to explore social movements and the power of aligning messaging to support a common goal (1986). The GAPD is calling for a global approach to dementia (WHO, 2017) that may be considered a social movement to push for inclusion and justice for PLWD, which aligns with the messages about their human rights. Therefore, framing messages to align with a rights-based approach may have the power to shift societal attitudes and beliefs and include PLWD as equals citizens in society.

Bosco and colleagues work emphasizes the power PLWD have to shift societal beliefs about dementia by owning their identity as a person living with dementia and advocating for themselves through messaging via media (2019). PLWD interpret the messages they receive about dementia and rely on self-awareness of their condition to act as agents to advocate for themselves by responding to messages. Through assertive responses, PLWD have the power to shift societal attitudes and beliefs about dementia and disrupt the power imbalance created by the framers of the initial messaging. I will use Bosco and colleagues' work as a guide to link message content with the intended

receiver to determine whether messaging is inclusive of PLWD which would be aligned

with a rights-based approach. It is not possible to determine the meaning PLWD may

derive from the messaging because it is outside the scope of this study, but the

perspective of PLWD must be contemplated when exploring a rights-based approach.

Therefore, I analyzed dementia messages as having the potential to engage PLWD to own

their identity and advocate for themselves by asking what message is being conveyed and

who the intended receiver may be.

IV. METHODS

An ethnographic content analysis of website homepages was conducted using a purposive sample of 36 ADI member associations representing countries (*N*=36) from the 6 geographic regions as indicated by the WHO (Africa, The Americas, Eastern Mediterranean, European, Southeast Asia, and Western Pacific) (Alzheimer's Disease International, 2021.c) (See Figure 1 and Appendix A). ADI members are non-profit organizations that represent their country of origin, have completed ADI's 2-year development programme and support PLWD and their families. Additionally, only one organization per country is allowed ADI membership (Alzheimer's Disease International, 2021.b). ADI member countries, through their representative associations, have shown a commitment to addressing dementia at a global level by signing the GAPD and being held accountable for meeting their goals through ADI membership.

Figure 1. Countries Represented in the Study Sample (*N*=36)

Data Collection

Website homepage data were collected during March and April 2021. Due to the changing nature of website content over time, screenshots were used to capture content during a specific timeframe. Multiple shots were taken where scrolling images were embedded in the webpage so that all content in the body of the homepage was captured. Google Translate was used to translate pages that were not in English. Because Google Translate has limited capacity to translate website content, only website homepages that contain greater than 50% of the total messages in English were included. One country association website was excluded for this reason.

Sections of website homepage content were considered individual messages based on how the content was visually delineated within the body of the homepage. Images that included embedded text were counted as a single message delivered in both text and image format. Some homepages contained full text articles. In these cases, only the title and images contained within full articles were included in the analysis. Messages that contained information not related to dementia were excluded.

Themes and Sub-themes

Ethnographic content analysis is a reflexive process of data collection, analysis and interpretation that uses purposive and theoretical sampling where the goal of the research is discovery or verification (Altheide, 1987). Some pre-structured categories are used in this method, but the emphasis is on allowing new concepts to emerge and to capture meaning in what is being communicated, using narrative and statistical analysis. Therefore, homepages were initially reviewed, using open coding and a constant reflective process to identify themes and subthemes. Themes were created based on the

pre-structured variables: *focus* (disease, person, both), *attitude* (tragic, hopeful), *intended receiver* and *topic*. Categories for disease and person focus were drawn from the biomedical model of dementia and the work of Kitwood (1997), Kontos (2004, 2017, 2020), and Gerritzen (2020), and tragic and hopeful categories were based on the work of Ballenger (2017), Reed (2017), Lin & Lewis (2015) and Hebert & Scales (2019). Attention was given to any theme that arose that did not fit the aforementioned variable categories. No new themes were identified; however, multiple subthemes did arise. Sub-themes were developed to capture the complex nature of each message due to some messages containing more than one *focus*, *attitude* or *intended receiver*. New subthemes were constantly compared to existing subthemes, combined if the definition of the subtheme was conceptually congruent or newly created if a new sub-theme was warranted. All messages were systematically reviewed when any new sub-theme emerged or when a theme or sub-theme definition was further clarified. This process was necessary to ensure all messages were consistently coded, using the same theme and subtheme definitions. The author of this study was the sole coder of all data. Every effort was made to minimize researcher bias by using continuous self-reflection and critical reasoning.

Based on the biomedical approach to dementia all themes that arose during the open-coding process and related to biomedical perspective were categorized as *disease focused*. Themes pertaining to language and concepts of personhood and dementia citizenship were categorized as *person focused*. Those pertaining to the tragedy discourse literature were categorized as *tragic* and those pertaining to a positive person concept were categorized as *hopeful*.

Sub-themes identified within each message were coded as a category for the appropriate variable. All categories were initially dichotomous and represented as 0 or 1 where 0 indicates the absence of the code and 1 represents presence of the code. For example, text and images that referenced brain imaging are represented with a 1 for brain imaging and included as an indicator or sub-category of disease-focus which is a category for the variable *focus*. Text and images that referenced *community* or *support* are each represented with a 1 and identified as indicators of person-focus which is another category of the variable *focus* (see Table 1).

Table 1. Description of Message Content on National Associations' Website Homepages

	Category	Sub-category

Variable
  Category:
    Sub-category
	No. of messages (%)	No. of messages (%)

Focus		
Disease	92 (12.1%)	
Person	385 (50.7%)	
Both	67 (8.8%)	
Neither	216 (28.4%)	
Disease indicators:		
Brain		23 (3.0%)
Dementia statistics		19 (2.5%)
Disease		95 (12.5%)
Disease process		1 (.01%)
Prevention, cure, treatment		10 (1.3%)
Signs and symptoms		21 (2.8%)
Person indicators:		
Advocate		25 (3.3%)
Care partner		59 (7.8%)
Community		131 (17.2%)
Cultural Inclusion		6 (0.8%)
Dementia Friendly		1 (.01%)
Dyad		67 (8.6%)
Family		71 (9.1%)
Individualized		36 (4.6%)
Intergenerational		21 (2.7%)
Person		66 (8.5%)

Person-Centered		3 (0.4%)
Person/s living with dementia		50 (6.4%)
Support		116 (14.9%)
Support Group		19 (2.4%)
Attitude		
Tragic	52 (6.8%)	
Hopeful	160 (21.0%)	
Both	4 (0.5%)	
Neither	544 (71.6%)	
Tragic indicators:		
Tragedy		45 (5.8%)
Flat/distressed affect		11 (1.4%)
Hopeful indicators:		
Positive		93 (11.9%)
Smiling		75 (9.6%)
Intended Receiver		
Person/s living with dementia	50 (6.6%)	
Care partner		59 (7.8%)
Family		71 (9.3%)
Healthcare Provider		8 (1.1%)
Researcher		4 (0.5%)
Topic		
Donation		48 (6.2%)
Education		44 (5.6%)
Event		98 (12.6%)
Information		278 (35.6%)
Music		10 (1.3%)
News		47 (6.0%)
Policy		7 (0.9%)
Quality/Safety		4 (0.5%)
Research		32 (4.1%)
Service		11 (1.4%)
Virtual Connection		29 (3.7%)
Volunteer		21 (2.7%)
Message Type		
Text		569 (72.9%)
Image		273 (35.0%)
Logo		7 (0.9%)
Untranslated		53 (6.8%)

All coding and variable development was guided by language and principles from the literature and theoretical approaches mentioned above. Individual message content alone does not adequately explain or reflect the meaning of the message. To gain a better

understanding of the possible meaning homepage messages are conveying, the context in which each message is embedded must be considered. Images positioned beside text, or individual messages arranged on a page may form a constellation that changes meaning when considered as a whole. Therefore, messages were examined in context of the entire website and surrounding messages on the homepage to determine which theme was most appropriate. Some themes were determined based on specific words that have intentional meaning in the dementia literature such as "person living with dementia". This phrase is known as an indicator of a positive person approach.

Analysis

Message content was manually coded, using Atlas.ti9 qualitative software, and then uploaded to SPSS for further analysis. Quantitative comparative analysis was conducted, using variables that represent the *topic*, *focus*, *attitude* and *intended receiver*. Messages were initially analyzed individually then collectively by country association and lastly inclusive of all country associations. Messages by country association were compared using percentages due to the significant difference in the number of messages per site. Frequencies, percentages, and mean scores were run in SPSS for all themes. Categories were created for each variable and recoded to create variables that could be compared individually and collectively per site. It was not possible to use the number of indicators for each variable as a measure of which *focus* or *attitude* an individual message is conveying for two reasons: (1) there were an uneven number of indicators for the categories of disease ($n=6$) and person ($n=14$), and (2) some messages contained indicators of both categories. Therefore, an additional category was created to capture messages that contained indicators of both categories. Additionally, percentages of

different types of messages per country were compared due to the difference in number of messages per site (min=2, max=45).

Frequencies and percentages of messages for the United States Alzheimer's Association were determined for each variable. Further analysis of each indicator or sub-category was conducted to get a clearer understanding of what topics were being discussed and how they were being framed. Messages were individually and collectively analyzed in context of the entire site. Further, messages were qualitatively analyzed by comparing the quantitative data with the descriptions of the themes used to create the codebook, theoretical concepts of social constructionism, personhood, citizenship, and the biopsychosocial approach. The homepage was reflected on as multiple messages embedded in the context of the entire site to determine the overall approach of the site.

Messages were quantitatively considered rights-based if they were person or both focused, did not contain indicators of a tragic attitude, and included PLWD as the intended receiver. Messages were qualitatively considered rights-based if the content engaged PLWD in the conversation about dementia, included the voice of PLWD and their experience, and offered ways for others to better understand living with dementia from the perspective of person's effected by dementia.

Messages were also compared for balance at the individual message level and collectively at the homepage level. An individual message was considered balanced if a message contained indicators of both disease and person indicators, or both tragic and hopeful indicators. Messages at the homepage level were considered balanced in the context of surrounding messages and the homepage in its entirety.

V. RESULTS

The number and percentage of messages in the study sample of 36 national associations (*N*=760) are described in Table 1. Indicators for each category and sub-category for both pre-structured variables (*focus*, *attitude*, *intended receiver* and *topic*) and descriptive variables (message type and translation) are presented.

Frequency distributions and percentages for each variable, category and sub-category revealed that 50% of the messages from 36 national associations were person focused, 12.1% were disease focused, 8.8% contained indicators of both disease and person focus, and 28.4% were neither. A hopeful attitude was conveyed in 21% of messages, 6.8% were tragic, 71.6% were neither, and .05% contained indicators of both a tragic and hopeful attitude. PLWD were the intended receiver of 6.6% of all messages. Family and care partners were the intended receivers of 9.3% and 7.8% of all messages. Information and events were the most frequently observed topics. More messages were delivered by text (72.9%) then image (35.0%) and 6.8% of messages were unable to be translated to English for analysis. Most messages were person focused, intended for families of PLWD, and delivered with neither a tragic nor hopeful attitude.

Analysis of 35 messages identified on the United States Alzheimer's Association website homepage showed that messages were somewhat more person focused (45.7%) than diseased focused (31.4%). Most messages did not identify a specific intended receiver. Messages that contain both a disease and person focus reflect messages about dementia that were delivered in a person-focused way. Only 2.9% of messages on the Alzheimer's Association homepage contain indicators of both a disease and person focus, and 11.4% of all the messages conveyed a hopeful attitude. No messages with both a

disease and person focus were also hopeful in attitude or were specifically intended for

PLWD. Messages intended specifically for PLWD comprised less than 12% of all

messages on the homepage and were equally intended for PLWD and care partners. No

messages were specifically intended solely for PLWD. See Table 2.

Table 2. United States Alzheimer's Association Messages

Variable Category: Sub-category	No. of messages (%)
Focus	
Disease indicators:	
Brain	2 (5.7%)
Dementia statistics	4 (11.4%)
Disease	7 (20.0%)
Disease process	1 (2.9%)
Prevention, cure, treatment	2 (5.7%)
Signs and symptoms	2 (5.7%)
Person indicators:	
Advocate	1 (2.9%)
Care partner	3 (8.6%)
Family	0 (0.0%)
Community	2 (5.7%)
Cultural inclusion	0 (0.0%)
Dementia friendly	0 (0.0%)
PLWD	3 (8.6%)
Dyad	1 (2.9%)
Individualized	1 (2.9%)
Intergenerational	1 (2.9%)
Person	3 (8.6%)
Person-centered	0 (0.0%)
Support	7 (20.0%)
Support Group	2 (5.7%)
Attitude	
Tragic indicators:	
Tragedy	7 (20.0%)
Flat/distressed affect	0 (0.0%)
Hopeful indicators:	
Positive	0 (0.0%)
Smiling	4 (11.7%)
Intended Receiver	
PLWD	3 (8.6%)
Care partner	3 (8.6%)
Family	0 (0.0%)

Healthcare provider	0 (0.0%)
Researcher	1 (2.9%)
Topic	
Donation	6 (17.1%)
Education	3 (8.6%)
Event	6 (17.1%)
Information	8 (22.9%)
Music	0 (0.0%)
News	1 (2.9%)
Policy	0 (0.0%)
Quality/safety	0 (0.0%)
Research	7 (20.0%)
Service	0 (0.0%)
Virtual connection	2 (5.7%)
Volunteer	3 (8.6%)
Message Type	
Text	29 (82.9%)
Image	7 (20.0%)
Logo	0 (0.0%)
Untranslated	0 (0.0%)

The proportion of disease-focused messages for the United States was significantly greater (31.4%) than the average for all countries (13.0%) (See Figure 2 and Appendix C). The proportion of person-focused messages for the United States was 45.7%, nearing the average of 46.8% for all countries. Messages with both a disease and person focus were much lower (2.9%) than the average for all countries (11.7%). The greatest difference between the United States compared to other countries was in *attitude* with messages for the United States being 20% tragic compared to the sample mean of 6.2%. Hopeful attitude for the United States (11.4%) was closer to the sample mean (17.0%). PLWD were the intended receiver of 8.6% of messages for the United States compared to the sample mean of 6.5%.
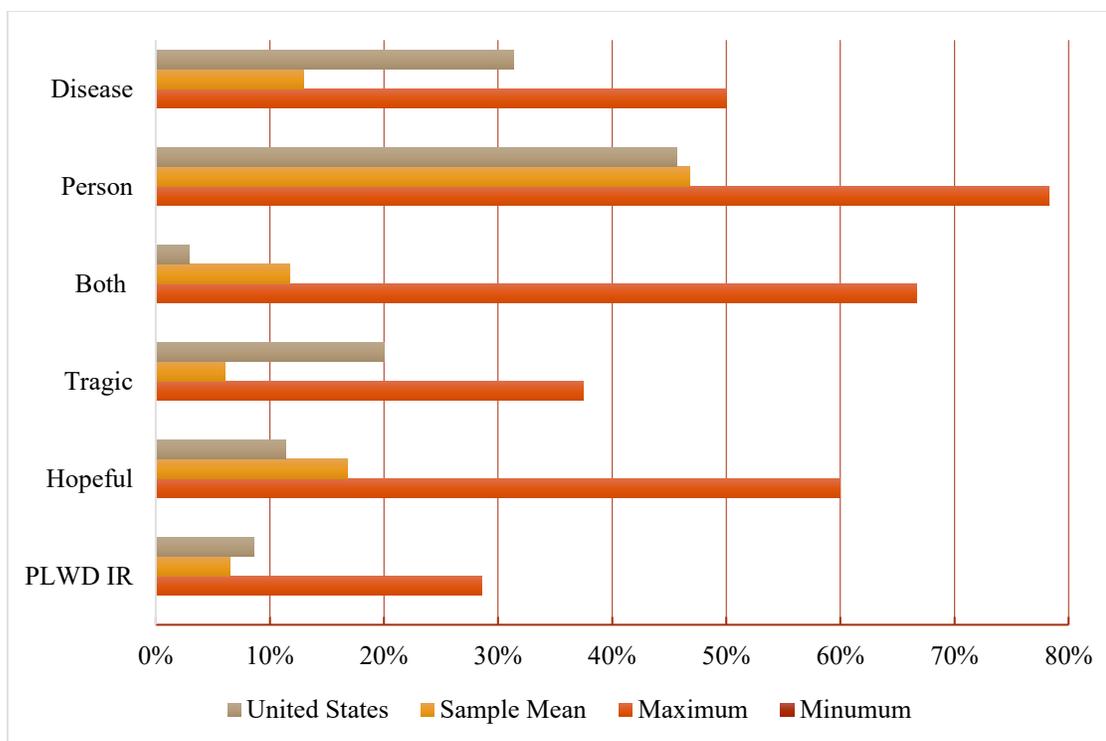
Figure 2. Comparison of U.S. Messages to Sample Mean

Comparing the United States Alzheimer's Association messaging with country associations with the highest percentages of disease and tragic focused messages shows that the United States has a smaller percentage of disease-focused messages than the country association with the highest percentage of disease-focused messages (i.e., Greece), and a greater percentage of tragic messages from the same country association (0.0%). In other words, the country with the highest percentage of disease-focused messages delivered them without depicting dementia as a tragedy. Although the United States contained a smaller proportion of tragic messages than those for the country with the highest percent of messages with a tragic attitude (i.e., Morocco), the homepage contained a greater proportion of disease-focused messages.

In comparison with country associations with the highest percentage of person-focused messages (i.e., the United Kingdom), the United States has a smaller percentage

of person-focused messages, greater percentage of tragic, and smaller percentage of hopeful messages and those intended for PLWD. The highest percentage of messages with a hopeful attitude was 60% (United Arab Emirates) which is much higher than the 11.4% from the United States.

The country association with highest percentage of messages with both a disease and person focus (Trinidad and Tobago) contained no messages with a tragic or hopeful attitude or PLWD as the intended receiver. Although, the proportion of U.S. messages intended for PLWD was higher than average, it was much lower than 28.6% from the Czech Republic. It is important to note that just because a message does not specifically address PLWD as the intended receiver it is not necessarily an indication that the message intended to exclude them. Figure 3 was not coded as a message intended for PLWD however, it does appear to include them.

Figure 3. Example of a Positive Person-focused Message not Specifically Intended for PLWD *(Retrieved from the Alzheimer's Disease Association Singapore 3/29/2021)*

The United States Alzheimer's Association homepage contained one positive person message. It was coded as hopeful attitude because it included an image of a person smiling. All hopeful messages for the United States were images. No messages delivered

via text were coded as positive. Figure 4 is an example of a positive person-focused

message from the United States.

Figure 4. Example of a Positive Person Message from United States *(Retrieved from The Alzheimer's Association in the United States on 3/31/2021)*

All messages that included PLWD as the intended receiver (*n*=50) met the criteria

for an individual message with a rights-based approach; person or both focused, does not

contain indicators of a tragic attitude and includes PLWD as the intended receiver. Sixty-

one percent of the country association homepages contained at least one individual rights-

based message. Figure 5 is an example of a message that uses a rights-based approach.

Figure 5. Example of a Message Framed Using a Rights-based Approach *(Retrieved from Spominčica – Alzheimer Slovenija 3/29/2021)*

This message includes reference to signs and symptoms of dementia, an activity that includes education and the arts for PLWD, seeks active participation through an invitation to attend an online event and offers community involvement. Alzheimer's Cafes offer connection, support and information sharing for people effected by dementia and the public (Alzheimer's Disease International, 2021.a.). The United States Alzheimer's Association homepage contained 3 rights-based messages. All of which were messages providing information about support groups.

Examining messages from a qualitative perspective, in the context of surrounding messages and the entire homepage collectively allows for more meaningful understanding of a rights-based approach and a balanced focus. Figure 6 is an example of three individual messages that combine to form a single message distinct from its individual parts. Two of the messages are disease focused with a neutral attitude. The third is person focused with a hopeful attitude. Without looking at the messages in context of each other, the individual messages appear unbalanced and not supportive of a rights-based approach. However, juxtaposed with the photo that depicts what appears to be a PLWD actively participating in an enjoyable activity with children, the overall message becomes more balanced.
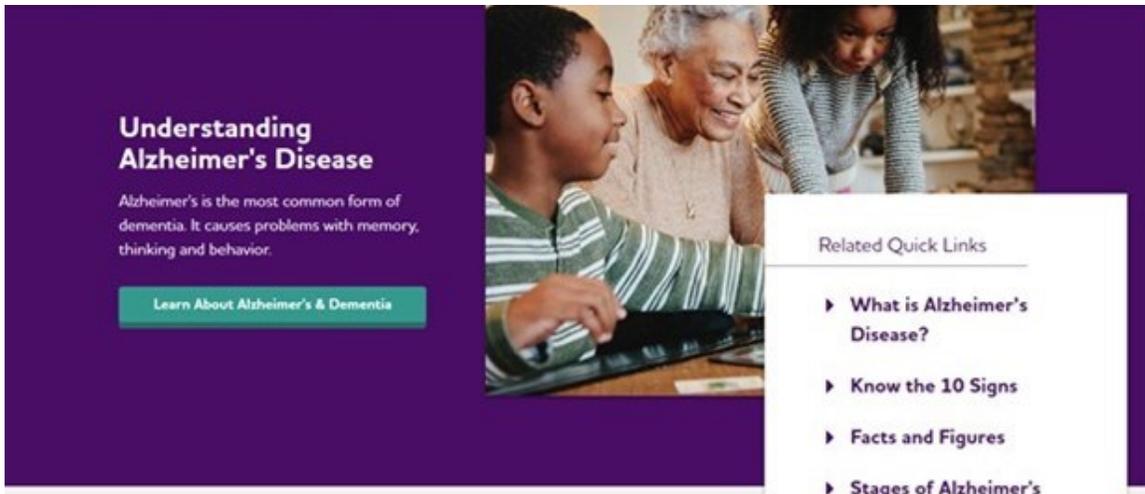
Figure 6. **Example of an Individual Messages in Context** *(Retrieved from The Alzheimer's Association in the United States on 3/31/2021)*

Taken one step further, messages must be viewed in the context of the entire homepage. The opening messages on the homepage of the United States Alzheimer's Association seen in Figure 7 helps explain why.

Figure 7. Example of Message Positioning *(Retrieved from The Alzheimer's Association in the United States on 3/31/2021)*

The position of this message as the first message viewers receive about dementia influences the following messages and the balance of all messages that follow. When the viewer scrolls down from this message, they are engaging with the next message from a perspective that is entirely disease focused. To balance the perspective, the following message would have to be heavily weighted toward a positive person perspective to

balance the overall effect of the message. Balanced individual messages alone would not

necessarily balance the overall message from the organization.

VI. DISCUSSION

The purpose of this study was to examine and compare public messaging about dementia in the United States with dementia messaging in other countries guided by the World Health Organization's Global action plan on the public health response to dementia using a rights-based approach. The research questions were: What message is being conveyed to persons living with dementia, their care partners, and the public about dementia in the United States? Who is the intended receiver of the message? Does the messaging align with the global dementia care plan for a rights-based approach to dementia? How does dementia messaging in the United States compare to other countries? How do messages vary? The results indicate that the United States through their representation organization, The Alzheimer's Association, conveys person-focused tragic disease messaging that includes PLWD as the intended receiver and is not aligned with other countries or a rights-based approach to dementia. The average messaging of all countries in the study was person focused, intended for families of PLWD, and delivered with neither a tragic nor hopeful attitude.

Messages Conveyed to Persons Living with Dementia in the United States

Messaging on the United States Alzheimer's Association website homepage is more tragic disease focused than the average of the sample (N=36). The larger proportion of tragic messaging negates a rights-based approach despite having a greater percentage of individual messages with a person focus. Meanwhile, the Association's messages include PLWD as the intended receiver of messages more frequently than the average of all other countries in the study and are more person focused than disease focused. They cover topics of donation, research, events, and general information more than any other

32

topics. The overall message is that dementia is a tragic disease, people diagnosed with it and their care partners need support, and the Alzheimer's Association is there to help by providing knowledge about the disease and raising money for research through fundraising events and donations.

Intended Receivers

Homepage messages that include PLWD as the intentional receiver of the information may provide a sense of inclusion, but they may unintentionally contribute to the social isolation of PLWD if the message frames dementia as a tragic disease. Reed and colleagues describe transcending the tragedy discourse of dementia as an ethical imperative and offers "mobilizing beliefs" to do so (2017, p. 699). It is impossible to know what message anyone is receiving from viewing dementia association homepages without conducting another study to do so. This study can only draw inferences from the present findings and provide a foundation for further investigations. However, it can provide insight into what message people might receive. If the goal is to avoid messaging that may increase stigma and social isolation for PLWD and their care partners, then careful attention must be taken when framing messages so that there is little chance the wrong message will be received. Messages that are positive and person focused will have a greater chance of conveying a sense of inclusion for PLWD and their care partners. The results of this study suggest that the United States as represented by the Alzheimer's Association has not framed their messaging to avoid potentially excluding PLWD or provided messages that empower PLWD with a sense of autonomy, equality, self-determination, participation, and inclusion.

Rights-based Approach

Key elements of a rights-based approach are avoiding tragic disease messaging and framing messages in a way that empower PLWD, their unique contributions to their communities, their ability to manage themselves autonomously and their inclusion in society. However, promoting empowerment of PLWD may not have desired outcomes if the context in which empowering messages are delivered is not considered. For example, messages that contain information about prevention and what measures can be taken to avoid getting dementia may be received by PLWD as blame for their condition. Leibing argues for the promotion of "situated prevention" strategies and highlights the absence of messaging that includes the socioeconomic factors of prevention (2018, 705). Similar to this present study, her analysis of preventive research projects revealed a disconnect between the approaches of United States and those of other countries. Interestingly, she used national dementia association website content as a source of data collection.

Promoting the rights of PLWD is complicated by factors that are sometimes overlooked. Fletcher examined the meaning of dementia for PLWD and contrasted that with the biomedical "Alzheimerised senility" of dementia (2020, p. 56). PLWD can become disconnected from society due to discrepancies between what they are experiencing and what the medical community describes dementia to be. The possibility of disconnection needs to be considered in dementia messaging, and that is why it is essential to include the voices of PLWD and their care partners in developing strategies for dementia care and research. Website homepages that prompt activities, workshops, and information about how PLWD can advocate for themselves are framing dementia using a rights-based approach that includes these multiple factors. The United States

Alzheimer's Association messaging is lacking these essential elements as revealed in this study.

United States Messaging Compared to other Countries

Data from this study show that the United States as represented by the Alzheimer's Association is out of alignment with the rest of the countries in the study many of which established their associations around the same time as the United States (1980): Canada (1978), Japan (1980), and the United Kingdom (1979). See Appendix A for more information about selected characteristics of sampled national associations. Compared with the United States, the United Kingdom as represented by the Alzheimer's Society had no disease-focused messages on their homepage (vs. 31.4%), and 78.3% (vs. 45.7%%) of their messages were person focused, 4.3% (vs. 20%) were delivered with a tragic attitude, and 17.4% (vs. 11.4%) were hopeful. Furthermore, they included PLWD as the intended receiver in 17.4% (vs. 8.6%) of all messages contained on the homepage. In comparison to the United States, the United Kingdom is doing a better job of balancing the focus and promoting a rights-based approach.

Roger Marple, a Canadian living with dementia, explained that in order to balance messaging about dementia, a greater percentage of focus needs to be put on the positive aspects and what can be done about dementia because anyone facing a diagnosis of dementia is coming to sources of information with an overwhelming sense of dementia as a "sea of despair," (2021). He also advises others living with dementia to seek information and support from their local dementia association. This can be detrimental if your local association does not promote a positive person focus. Early diagnosis is currently a high priority, and strategies to remove barriers to early diagnosis hinge on

decreasing the stigma and fear around dementia. If you fear you might have dementia and the messaging you receive from your local association lacks strong positive person messaging, you may further delay an assessment. According to the World Alzheimer's report 2021, 60% of people in high income countries and 90% of people in low-income countries are undiagnosed, and 55% of those diagnosed have inadequate follow up after diagnosis because 60% of clinicians believe nothing can be done about dementia (Gauthier, et al., 2021). What does this information mean for the millions of PLWD and their care partners? Associations that are the sources of information and where people are referred to for information must include a significant percentage of positive person messaging in order to balance the overwhelming negative beliefs about the disease of dementia. This is imperative for diagnosis and for learning that it is possible to live a meaningful life with dementia.

Variations in Messaging

Messages from other countries in the sample are generally conveyed with a focus on the person living with dementia, involving PLWD and their care partners in their communities and emphasizing ways to live a meaningful life with dementia. Messaging like this shifts power from an external source where PLWD are passive in their care to an internal source that empowers PLWD as agents in the construction of their own life experience.

Positive person messaging also focuses on what can been done right now to improve life with dementia. Messaging on the United States Alzheimer's Association website conveys the message that what can be done right now is funding research, being a research participant, learning about Alzheimer's disease and joining a support group.

These are all powerful ways to help PLWD and their care partners, but they do not empower them as agents of their situation. The power lies with researchers and others that can provide support. The message is unbalanced and leans toward dependence rather than the principles of personhood and citizenship: interdependence, contribution to the community, the uniqueness of each individual with dementia, and agency as promoted by Kitwood (1997), Bartlett (2007), Kontos and colleagues (2017).

Themes and subthemes identified in this study are like those found by Mehta and colleagues in their analysis of health forums and twitter (2020). Although their study investigated these platforms for different purposes than this study, they identified information exchange and requests by care partners for support, which are in line with the themes found on the homepages in this study. The current study provides information about various topics associations believe are important as well as another perspective of dementia messaging. The perspective of dementia association as the framers of dementia messaging can be combined with Mehta and colleagues' approach and used to examine messaging where the framer of the messages are PLWD, care partners and the public. Through these interactions, beliefs and attitudes are enacted and the experience of living with dementia is constructed. Multiple viewpoints in the approach to messaging could have powerful implications for determining what messages are being received, what the responses to the messages are and what experience is being created.

Challenges and Limitations

The process of assigning sub-themes to variable categories required reflective critical thinking and challenging my own beliefs and attitudes. A prominent example was distinguishing tragic messages from those that conveyed urgency. Interpreting with

underlining meaning was challenging for quantitative categorization and is more reflected in the analysis of messages in context. Another researcher may interpret the meaning differently. The influence of my attitudes and beliefs on the study is unavoidable. However, they are primarily shaped by the words and voices of PLWD through my personal experiences, and the sociological study of dementia. Further analysis and inclusion of PLWD and their care partners in the research process may reveal insights not captured in this study.

There are several limitations of this study. The use of only one coder limits the reproducibility of the study. Future studies should be critically reviewed by more than one coder and ideally by at least three for consensus. Only 36 of the 106 countries that signed the GAPD were included in the study. Although all 6 geographic areas of the world are represented, there are more from European countries than any other area which could skew the data toward a predominant cultural perspective. A more diverse sample may provide more comprehensive data. Only the body of website homepages were included in the coding process. Future studies should include messaging on the entire website. As stated previously, collecting data from website users could have a significant impact on the interpretation of messages, especially from the perspective of persons living with dementia. This would give more strength to the validity of the themes and reliability of message interpretation. Further analysis of other factors such as population, income, type and mission of associations, and association funding sources may provide a better understanding of what influences messaging. Countries differ in the way government funds are allocated for research and healthcare which may, in turn, influence how messages are framed and who the intended receiver of the message is. For example,

messaging in countries with universal healthcare is likely to be different than countries without. Data regarding these differences were not part of this study. The current investigation did not address these factors, which were beyond its scope.

Results of this study were as expected other than the variation in number of messages per homepage. The sample chosen may have influenced the data in ways that skew toward a collective perspective as some of the country associations are affiliated with one another and European countries may be overrepresented in this study. Future studies should consider including more countries with differing cultural values. Although all agreed with the rights-based values of the GAPD, how those values are enacted at the country and local levels may differ.

Implications

Dementia messages that support a rights-based approach convey dignity, respect, autonomy, and equality for PLWD and their right to self-determination, independence, participation, and inclusion. They contain topical information that is dementia related, place the person living with dementia and their care partners at the center, are absent of hyperbolic language and tone, and address PLWD as agents of their own wellbeing. Most importantly, they have the power to influence attitudes, beliefs, and the reality of living with dementia. Messages framed by the sender reflect the values of an individual, organization, nation, or global community. To reflect the values of a rights-based approach to dementia, dementia associations must consider how they are framing the messages on their website individually and collectively. The language and tone of messages should reflect the values of dignity, respect, autonomy, and equality for PLWD and their right to self-determination, independence, participation, and inclusion. The

GAPD has outlined a public health agenda at the global level. Countries, through their representative associations, have also developed goals and plans in line with the GAPD outline. This macro approach can be narrowed down to the micro level by creating a clear path from the national level to the local and individual level by including person's living with dementia, their care partners and communities in the goal setting and planning processes. Including people effected by dementia in goals setting and planning for dementia care, services and research puts the values of a rights-based approach into action and empowers them as agents in their own lives. It also may avoid developing programs and services that are not priorities for PLWD.

The person-focused approach and hopeful attitude of the message shifts the power from those that provide dementia services, resources, and knowledge to those that receive them. Balancing the approach to include persons effected by dementia empowers them as active participants in their own lives and the future of others like them. In absence of inclusion of persons effected by dementia as active participants, the power remains unbalanced in favor of those of the observers of dementia not the people living with the diagnosis. The attitudes and beliefs created by the framer of the message are enacted at the micro level through behaviors displayed during social interactions embedded in the cultural environment, and at the macro level through public health initiatives where the priorities of PLWD may not align with the priorities of others (Haapala, Carr, A & Biggs, 2019).

Harding and Palfrey (1997) describe the social construction of dementia as a situation that is bred by people positioning PLWD outside social norms. Persons living with dementia have the power to be active participants in the construction of the lived

experience of dementia through messaging in their own voice. Through active participation in the framing of messages, they can influence the shift of power from those that are observers of dementia to include those that are living with the diagnosis. If the lived experience of dementia is created during social interactions and messages received about dementia, those messages must be framed in alignment with our values. When people with dementia are referred to a dementia organization for information after being diagnosed, the message they receive should be a balanced one that values social inclusion just as much as science and biomedical research.

Referrals to resources after diagnosis should be to places and entities that provide an integrated perspective and not limit information to any one aspect of dementia. Providing information about dementia, the diseases and conditions that cause dementia, and what is possible for PLWD can balance messaging in ways that shift the power of dementia from the disease to the person. Dementia resources that include information about what PLWD can do to advocate for themselves, how they can work in collaboration with their care partners, and how people in all societies can contribute to their communities by creating inclusive environments for PLWD can empower PLWD as citizens with agency.

If our goal is to help people live better with dementia, then messaging from the United States Alzheimer's Association needs to change because according to the literature, tragic disease messaging does not feel inclusive of PLWD or productive for well-being. That is not to say understanding disease and the disease process is not important. It just cannot be the predominant message. People living with dementia are more than a disease. They are unique whole persons that contribute to research, their

families, and their communities well into the later stage of dementia. Unfortunately, that is not the message you get if you go to the United States Alzheimer's Association website. It is important to note, however, that the Alzheimer's Association must rigorously compete with other agencies within the United States for limited funding. Hence, messages may be driven by this competition and intentionally focus on the tragic disease of dementia to highlight the need for funding. Framing messages based on what information is required to reach a specific audience as suggested by Goffman's concept of audience segregation (Barnhart, n.d.) may be what is necessary to meet the complex needs of dementia care.

VII. CONCLUSION

Messages are not just about how and what information is delivered, they are also about what the sender of the message values. Country associations provide information through their website homepages and what they value is reflected in what it contains, the topics they cover and how the messages are arranged on the page. These aspects and more reflect what is important to the organization and the attitudes, beliefs, and topics they value. The emphasis on dementia as a tragedy socially isolates people with dementia, and perpetuates stigma and stereotypes (Ballenger, 2017). Messages that empower PLWD as their own agents to support themselves and collaborate with others in community and support a rights-based approach are currently missing from the U.S. Alzheimer's Association homepage.

The Alzheimer's Association of the United States was established in 1980 at the beginning of the "war on dementia". The focus of dementia as a disease that needed to be cured was at the forefront of research and as such, the messaging of dementia as a tragic disease was beneficial then. However, that message is no longer satisfactory for PLWD or for society working to find ways of improving lives while living with dementia. To align with a more positive person-focused rights-based approach of the GAPD, the Alzheimer's Association should consider shifting their messaging in support of a positive attitude and what is possible now for people effected by dementia. This is especially important as dementia awareness campaigns through public health priorities are increasingly referring people to the Alzheimer's Association for dementia resources (Olivari et al., 2020).

The United States Department of Health and Human Services (HHS) recently

43

launched a website that appears to be more positive person focused (Alzheimers.gov, 2021). Hopefully the efforts of HHS to address the needs of persons with dementia will balance the messaging in the United States to align with the values of a rights-based approach and the construction of a meaningful life with dementia. The power, influence, and recognition of the Alzheimer's Association as the premiere resource for dementia information in the United States would be challenging for HHS to overcome in an effort to balance dementia messages. However, that may not be necessary if the Alzheimer's Association and Alzheimers.gov created a collaborative partnership. Doing so could send a powerful message that we are all in this together and the United States does indeed believe "…that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness," (U.S. Constitution, pmbl) including people living with dementia.

This empirical investigation provides evidence that fills a gap in dementia literature regarding national and global dementia messaging. These findings contribute to the body of dementia literature by providing an observer perspective of the content and delivery of dementia messaging by national associations around the world. Further, these findings can be a resource for associations as they consider evolving their websites to suit the changing needs and receivers of their website content as greater numbers of PLWD seek information themselves. PLWD may be the intended or unintended receiver of messaging that previously focused on the care partner as the intended receiver. This study frames the voice of PLWD at the center of dementia messaging and urges those with the power of influence to share that power by using a positive person approach that includes the voice of PLWD and their care partners at every stage.

APPENDIX SECTION

Appendix A: Characteristics of Country Associations

WHO Region	Country	Association	Website	Homepage Translated	Year Established	Year of ADI membership	Type of organization	Affiliation
West Pacific	Australia	Dementia Australia	https://www.dementia.org.au/	No	2017	1985	N/A	N/A
European	Austria	Alzheimer Austria	https://www.alzheimer-selbsthilfe.at/	Yes	N/A	1993	N/A	Alzheimer Europe
European	Belgium	Ligue Nationale Alzheimer Liga	https://alzheimer-belgium.be/	Yes	N/A	1986	Network	Alzheimer Europe
West Pacific	Brunei Darussalam	demensia Brunei	https://sites.google.com/prod/view/demensiabrunei/home	Yes	2018	2020	Association	N/A
Americas	Canada	The Alzheimer Society of Canada (ASC)	https://www.alzheimer.ca/	No	1978	1984	Federation	N/A
West Pacific	China	Alzheimer's Disease Chinese (ADC)	https://www.adc.org.cn/	Yes	2002	2002	National branch of the Chinese Geriatric Health Association	N/A
Americas	Costa Rica	Asociación Costarricense de Alzheimer y otras Demencias Asociadas (ASCADA)	https://ascadacr.wordpress.com/	Yes	N/A	2000	Association	Alzheimer Iberoamerica
European	Cyprus	Cyprus Alzheimer Association and Related Dementias	https://cyprusalzheimerassociation.weebly.com/	Yes	1996	2000	Association	Alzheimer Europe

WHO Region	Country	Association	Website	Homepage Translated	Year Established	Year of ADI membership	Type of organization	Affiliation
European	Czech Republic	Česká alzheimerovská společnost	http://www.alzheimer.cz/	Yes	1996	1997	Association	Alzheimer Europe
European	Denmark	Alzheimerforeningen	https://www.alzheimer.dk/	Yes	N/A	1991	Association	Alzheimer Europe
European	Estonia	Living with Dementia / MTÜ Elu Dementsusega	http://www.eludementsusega.ee/	Yes	2016	2019	NGO	4 partners
European	Finland	The Alzheimer Society of Finland	http://www.muistiliitto.fi/	Yes	1988	1989	Association	Alzheimer Europe
European	France	France Alzheimer	https://www.francealzheimer.org/	Yes	1985	2020	Association	Alzheimer Europe
European	Germany	Deutsche Alzheimer Gesellschaft	https://www.deutsche-alzheimer.de/	Yes	1989	1989	Association	Alzheimer Europe
European	Greece	The Panhellenic Federation of Alzheimer's Disease and Related Disorders	http://www.alzheimer-federation.gr/	Yes	2007	1996	Federation	Alzheimer Europe
Southeast Asia	India	Alzheimer's & Related Disorders Society of India (ARDSI)	http://www.ardsi.org/	No	1992	1994	Association	STRiDE
European	Ireland	The Alzheimer Society of Ireland	http://www.alzheimer.ie/	No	1982	1986	Society	Alzheimer Europe

WHO Region	Country	Association	Website	Homepage Translated	Year Established	Year of ADI membership	Type of organization	Affiliation
West Pacific	Japan	Alzheimer's Association Japan (AAJ)	http://www.alzheimer.or.jp/	Yes	1980	1992	Association	N/A
Africa	Kenya	Alzheimer's & Dementia Organisation Kenya (ADOK)	http://www.alzkenya.org/	No	2016	2017	Association	STRiDE
Eastern Mediterranean	Lebanon	Alzheimer's Association Lebanon (AAL)	http://www.alzlebanon.org/	No	2004	2004	Association	N/A
European	Malta	The Malta Dementia Society	http://www.maltadementiasociety.org.mt/	No	2004	2006	Association	Alzheimer Europe
Africa	Mauritius	The Alzheimer Association of Mauritius	http://www.alzheimer-mauritius.com/	No	2005	2009	Association	N/A
E Med	Moroco	Association Maroc Alzheimer (AMA)	http://www.marocalzheimer.ma/	Yes	2003	2020	Association	N/A
European	Netherlands	Alzheimer Nederland	http://www.alzheimer-nederland.nl/	Yes	1984	1989	Association	Alzheimer Europe
European	Norway	Nasjonalforeningen for folkehelsen	http://www.nasjonalforeningen.no/	Yes	N/A	2014	Association	Alzheimer Europe
Eastern Mediterranean	Pakistan	Alzheimer's Pakistan	http://alz.org.pk/	No	2000	2001	Association	N/A
European	Russia	Foundation Alzrus	https://www.alzrus.org/	Yes	2009	2012	Association	N/A
West Pacific	Singapore	Alzheimer's Disease Association Singapore	https://alz.org.sg/	No	1990	1995	Association	N/A

WHO Region	Country	Association	Website	Homepage Translated	Year Established	Year of ADI membership	Type of organization	Affiliation
European	Slovenia	Spominčica – Alzheimer Slovenija	http://www.spomincica.si/	Yes	1997	2014	Association	Alzheimer Europe
European	Sweden	Alzheimer Sweden	https://www.alzheimersverige.se/	Yes	1986	1986	Association	Alzheimer Europe
European	Switzerland	Alzheimer Schweiz Suisse Svizzera	http://www.alz.ch/	Yes	1988	1990	Association	Alzheimer Europe
Southeast Asia	Thailand	Alzheimer's and Related Disorders Association of Thailand	http://www.azthai.org/	Yes	1998	1999	Association	N/A
Americas	Trinidad and Tobago	The Alzheimer's Association of Trinidad and Tobago	http://www.alztrinbago.org/	No	2000	2004	Association	N/A
Eastern Mediterranean	United Arab Emirates	4get-me-not Alzheimer's Organization – UAE	http://www.4get-me-not.org/	No	2013	2017	Association	N/A
European	United Kingdom	Alzheimer's Society	https://www.alzheimers.org.uk/	No	1979	1979	Association	Alzheimer Europe
Americas	United States	The Alzheimer's Association	https://www.alz.org/	No	1980	1984	Association	N/A

Appendix B: Codebook for themes presented on dementia association website homepages

Theme	Description
Advocate	Advocate for human rights for PLWD and Care partners, commitment to change, improve lives of PLWD and CP's
Brain	Image of the brain or the actual word "brain" is used
Care partner	Aim is the care partner including caregiving, carer, caring for a PLWD
Community	Depicts fellowship with others
Cultural Inclusion	Inclusive of cultural diversity (ethnicity, race, gender, sexuality, etc.)
Dementia Friendly	Specifically states "Dementia Friendly" and not captured by another code
Dementia Statistics	Statistics about dementia
Disease	General information about dementia ("what is dementia")
Disease Process	Specifies information about disease progression
Donation	Request for donation, fundraising, link to donation page ('Donate")
Dyad	Two people depicted in a photo
Education	Classes, teaching, training
Event	A planned public or social occasion
Family	Refers to family
Flat/distressed affect	Facial expression that is flat or distressed
Image	Photograph, drawing, graphic
Individualized	Considers the unique needs and/or situations of individuals living with dementia, their care partners and family
Information	General knowledge not otherwise specified concerning a particular fact or circumstance and/or link to "learn more" or "more information"
Intergenerational	Depiction of a child with older adult or refers to intergenerational event, workshop, etc.
IR-Healthcare Provider	Information specifically intended for healthcare providers

Theme	Description
IR-PLWD	Information specifically intended for persons living with dementia
IR-Researcher	Information specifically intended for researchers
Logo	Logo
Music	Refers to musical activity
News	Newly received or noteworthy information, especially about recent or important events; newsletter
Person	One person in photo/image
Person-Centered	Relays person-centeredness not otherwise specified
Policy	Refers to governmental changes, proposals, or initiatives
Positive	Refers to well-being, laughter, creativity, meaning, purpose, agency, engagement
Prevention, Cure, Treatment	Refers to preventative measures, cure for dementia and dementia treatment
Quality/Safety	Pertains to quality care and safety for PLWD
Research	Research is depicted in image that includes graphs, statistics, or tables. Text describes research or refers to research activities
Services	Refers to general services offered or mentions "serving" PLWD.
Signs and Symptoms	Refers to signs and symptoms of dementia
Smiling	Depicts a smiling face
Support	Mentions support for PLWD, family, care partner
Support group	Support group for care partners and/or PLWD
Text	Words, numbers
Tragedy	Includes tragic hyperbolic language and tone such as die, kills, suffering/er, crisis, beat, fight, burden, tackle
Untranslated	Message was unable to be translated to English
Virtual Connection	Refers to connecting to information or people via the internet
Volunteer	Refers to volunteers and volunteering

Appendix C: Comparison of U.S. Messages to Sample Mean

Number of Messages	Focus			Attitude			Intended Receiver
	Disease %	Person %	Both %	Tragic %	Hopeful %	Both %	PLWD %
United States *(35)*	31.4% (11)	45.7% (16)	2.9% (1)	20.0% (7)	11.4% (4)	0.0% (0)	8.6% (3)
Sample Mean *(21)*	13.0% (3)	46.8% (11)	11.7% (2)	6.1% (1)	16.8% (4)	2.2% (3)	6.5% (1)
Maximum	50.0%	78.3%	66.7%	37.5%	60.0%	50.0%	28.6%
Minimum	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%

REFERENCES

Altheide, D. L. (1987). Reflections: Ethnographic content analysis. *Qualitative Sociology 10*(1):65-77. https://doi:10.1007/BF00988269

Alzheimer's Association (2020, March 10). 2020 Alzheimer's disease facts and figures. *Alzheimer's Dementia.* https://doi.org/10.1002/alz.12068

Alzheimers.gov (2021, May 8). https://www.alzheimers.gov/

Alzheimer's Disease International (2021, March). *Alzheimer Cafés***.** https://www.alzint.org/what-we-do/policy/dementia-friendly-communities/alzheimer-cafes/

Alzheimer's Disease International (2021, March). *Member Associations*. https://www.alzint.org/our-members/member-associations/

Alzheimer's Disease International (2021, March). *Our members*. https://www.alzint.org/our-members/

Ballenger, J. F. (2017). Framing confusion: Dementia, society, and history. *AMA Journal of Ethics*, *19*(7), 713-719. https://doi:10.1001/journalofethics.2017.19.7.mhst1-1707

Barnhart, Adam D. (n.d). Erving Goffman: The presentation of self in everyday life. [Lecture notes] Portland State University. http://web.pdx.edu/~tothm/theory/Presentation%20of%20Self.htm

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, *21*(2), 107-118. https://doi.org/10.1016/j.jaging.2006.09.002

Benbow, S. M., & Jolley, D. (2012). Dementia: Stigma and its effects. *Neurodegenerative Disease Management, 2*(2), 165-172. https://doi:10.2217/nmt.12.7

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. Doubleday & Company.

Bosco, A., Schneider, J., Coleston-Shields, D. M., Higgs, P., & Orrell, M. (2019). The social construction of dementia: Systematic review and metacognitive model of enculturation. *Maturitas, 120*, 12-22. https://doi:10.1016/j.maturitas.2018.11.009

Burke, L. (2017). Imagining a future without dementia: Fictions of regeneration and the crises of work and sustainability. *Palgrave Communications*, 3(1). https://doi:10.1057/s41599-017-0051-y

Butchard, S., & Kinderman, P. (2019). Human rights, dementia, and identity. *European Psychologist*. 24(2), 159–168. https://doi.org/10.1027/1016-9040/a000370

Cahill, S. (2020). WHO's global action plan on the public health response to dementia: some challenges and opportunities. *Aging & Mental Health*, 24(2), 197-199. https://doi:10.1080/13607863.2018.1544213

Calvert, L., Keady, J., Khetani, B., Riley, C., & Swarbrick, C. (2020). '… This is my home and my neighbourhood with my very good and not so good memories': The story of autobiographical place-making and a recent life with dementia. *Dementia, 19*(1), 111-128. https://doi:10.1177/1471301219873524

Cheston, R., Hancock, J., & White, P. (2019). Does personal experience of dementia change attitudes? The Bristol and South Gloucestershire survey of dementia attitudes. *Dementia,* 18(7-8), 2596-2608. https://doi:10.1177/1471301217752707

CMI CHR. Michelsen Institute (n.d). *Operationalizing a Rights-Based Approach to Health Service Delivery*. https://www.cmi.no/projects/1791-operationalizing-a-rights-based-approach-to-health.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia* 6(1):11-25. https://doi:10.1177/1471301207075625

Fletcher, J. R. (2020). Mythical dementia and Alzheimerised senility: discrepant and intersecting representations of cognitive decline in later life. *Social Theory & Health*, *18*(1), 50-65. https://doi.org/10.1057/s41285-019-00117-w

Gauthier S, Rosa-Neto P, Morais JA, & Webster C. (2021). *World Alzheimer Report 2021: Journey through the diagnosis of dementia.* London, England: Alzheimer's Disease International. https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf

Gerritsen, D. L., Oyebode, J., & Gove, D. (2018). Ethical implications of the perception and portrayal of dementia. *Dementia*, 17(5), 596-608. https://doi.org/10.1177/1471301216654036

Gerritzen, E. V., Hull, M. J., Verbeek, H., Smith, A. E., & de Boer, B. (2020). Successful elements of intergenerational dementia programs: A scoping review. *Journal of Intergenerational Relationships*, *18*(2), 214-245. https://doi.org/10.1080/15350770.2019.1670770

Goffman, E. (1974). *Frame analysis: An essay on the organization of experience*. Harvard University Press.

Green, A. R., Carrillo, J. E., & Betancourt, J. R. (2002). Why the disease-based model of

    medicine fails our patients. *The Western journal of medicine*, 176(2), 141-143.

    https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1071693/

Haapala, I., Carr, A., & Biggs, S. (2019). What you say and what I want: Priorities for

    public health campaigning and initiatives in relation to dementia. *Australasian*

    Journal On Ageing, *38*, 59-67. https://doi.org/10.1111/ajag.12647

Harding, N., & Palfrey, C. (1997). *The Social Construction of Dementia: Confused*

    Professionals? Jessica Kingsley.

Hebert, C. A., & Scales, K. (2019). Dementia friendly initiatives: A state of the science

    review. *Dementia,* 18(5), 1858-1895. https://doi:10.1177/1471301217731433

Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the

    United States (2010–2050) estimated using the 2010 census. *Neurology, 80*(19),

    1778-1783. https://doi.org/10.1212/WNL.0b013e31828726f5

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and

    well-being. *Ageing and Society, 12*(3), 269-287.

    https://doi:10.1017/S0144686X0000502X

Kontos, P. C. (2004). Ethnographic reflections on selfhood, embodiment, and

    Alzheimer's disease. *Ageing & Society, 24*(6), 829-849.

    https://doi.org/10.1017/S0144686X04002375

Kontos, & Martin, W. (2013). Embodiment and dementia: Exploring critical narratives of

    selfhood, surveillance, and dementia care. *Dementia (14713012), 12*(3), 288-302.

    https://doi:10.1177/1471301213479787

Kontos, P., Miller, K.-L., & Kontos, A. P. (2017). Relational citizenship: Supporting

 embodied selfhood and relationality in dementia care. *Sociology of Health &*

 Illness, 39(2), 182-198. https://doi:10.1111/1467-9566.12453

Kontos, P., Grigorovich, A., Dupuis, S., Jonas-Simpson, C., Mitchell, G., & Gray, J.

 (2020). Raising the curtain on stigma associated with dementia: Fostering a new

 cultural imaginary for a more inclusive society. *Critical Public Health*, *30*(1), 91-

 102. https://doi.org/10.1080/09581596.2018.1508822

Leibing, A. (2018). Situated prevention: Framing the "New Dementia" [Article]. *Journal*

 of Law, Medicine and Ethics, *46*(3), 704-716.

 https://doi.org/10.1177/1073110518804232

Lin, S.-Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia

 positive: Concepts to prepare for the future. *The Gerontologist*, *55*(2), 237-244.

 https://doi.org/10.1093/geront/gnu122

Malterud, K., & Elvbakken, K. T. (2020). Patients participating as co-researchers in

 health research: A systematic review of outcomes and experiences. *Scandinavian*

 Journal of Public Health, 48(6), 617-628. https://doi:10.1177/1403494819863514

Mann, J. (2020). Canadian charter of rights for people with dementia. *Dementia, 19*(1),

 63-67. https://doi:10.1177/1471301219876503

Marple, R. [Alzheimer's Disease International] (2021, September 22). *World Alzheimer*

 report 2021 launch webinar: Journey through the diagnosis of dementia [Video].

 YouTube. https://youtu.be/QeLYka4sLlk

Mehta, N., Zhu, L., Lam, K., Stall, N. M., Savage, R., Read, S. H., Wu, W., Pop, P., Faulkner, C., Bronskill, S.E., & Rochon, P. A. (2020). Health forums and twitter for dementia research: Opportunities and considerations. *Journal of the American Geriatrics Society*, 68(12), 2881-2889. https://doi:10.1111/jgs.16790

Mitchell, G., Dupuis, S., & Kontos, P. (2013). Dementia discourse: From imposed suffering to knowing other-wise. *Journal of Applied Hermeneutics*, 0(2). https://doi.org/10.11575/jah.v0i2.53220

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, *8*(4), 377-386. https://doi.org/10.2217/ahe.12.42

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia*, 19(2), 148-181. https://doi:10.1177/1471301218800122

O'Connor, D., Mann, J., & Wiersma, E. (2018). Stigma, discrimination, and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies*, *44*, 45-51. https://doi.org/https://doi.org/10.1016/j.jaging.2018.01.010

Olivari, B. S., French, M. E., & McGuire, L. C. (2020). The public health road map to respond to the growing dementia crisis. *Innovation in aging*, *4*(1). https://doi.org/10.1093/geroni/igz043

Oliver, K., O'Malley, M., Parkes, J., Stamou, V., La Fontaine, J., Oyebode, J., & Carter,

 J. (2020). Living with young onset dementia and actively shaping dementia

 research – The Angela Project. *Dementia*, 19(1), 41-48.

 https://doi:10.1177/1471301219876414

Peel, E. (2014). 'The living death of Alzheimer's' versus 'Take a walk to keep dementia at

 bay': representations of dementia in print media and carer discourse. *Sociology of*

 Health & Illness, 36(6), 885-901. https://doi:10.1111/1467-9566.12122

Reed, P., Carson, J., & Gibb, Z. (2017). Transcending the tragedy discourse of dementia:

 An ethical imperative for promoting selfhood, meaningful relationships, and well-

 being. *AMA Journal of Ethics*, 19(7), 693-703.

 https://doi.org/10.1001/journalofethics.2017.19.7.msoc1-1707

Revoir, P. (2011) The living death of Alzheimer's. *Daily Mail*, 26 April.

Scottish Human Rights Commission (n.d.). *What is a human rights-based approach?*

 http://careaboutrights.scottishhumanrights.com/whatisahumanrightsbasedapproac

 h.html

Shah, H., Albanese, E., Duggan, C., Rudan, I., Langa, K. M., Carrillo, M. C., Chan, K.Y.,

 Joanette, Y., Prince, M., & Rossor, M. (2016). Research priorities to reduce the

 global burden of dementia by 2025. *The Lancet Neurology*, 15(12), 1285-1294.

 https://doi.org/10.1016/S1474-4422(16)30235-6

Shakespeare, T., Zeilig, H., & Mittler, P. (2019). Rights in mind: Thinking differently

 about dementia and disability. *Dementia*, 18(3), 1075-1088.

 https://doi:10.1177/1471301217701506

Snow, D.A., Rochford, E.B., Worden, S.K., & Benford, R.D., (1986). Frame alignment

      processes, micromobilization, and movement participation. *American*

      Sociological Review 51(4):464-81. https://doi: 10.2307/2095581

Spector, A., & Orrell, M. (2010). Using a biopsychosocial model of dementia as a tool to

      guide clinical practice. *International Psychogeriatrics*, *22*(6), 957-965.

      https://doi.org/10.1017/S1041610210000840

Stites, S. D., Johnson, R., Harkins, K., Sankar, P., Xie, D., & Karlawish, J. (2018).

      Identifiable characteristics and potentially malleable beliefs predict stigmatizing

      attributions toward persons with Alzheimer's Disease dementia: Results of a

      survey of the U.S. general public. *Health Communication, 33*(3), 264-273.

      https://doi:10.1080/10410236.2016.1255847

The Alzheimer's Association (2021, March 30). https://www.alz.org/

The Alzheimer's Association (2021, March 30). *Our Impact*.

      https://www.alz.org/about/our-impact

U.S. Constitution, pmbl.

Vernooij-Dassen, M., Moniz-Cook, E., Verhey, F., Chattat, R., Woods, B., Meiland, F.,

      Franco, M., Holmerova, I., Orrell, M., & de Vugt, M. (2021). Bridging the divide

      between biomedical and psychosocial approaches in dementia research: The 2019

      INTERDEM manifesto. *Aging & Mental Health*, 25(2), 206-212.

      https://doi:10.1080/13607863.2019.1693968

WHO, World Health Organization. (2017). Global action plan on the public health

    response to dementia, 2017–2025. Geneva:World Health Organization.

    https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-

    response-to-dementia-2017---2025

Wolverson, E. L., Clarke, C., & Moniz-Cook, E.D. (2016). "Living positively with

    dementia: A systematic review and synthesis of the qualitative literature." *Aging*

    & Mental Health 20(7):676-99. https://doi: 10.1080/13607863.2015.1052777