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Alzheimer's Disease, Media Representation, and Audience Reception

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Abstract

The purpose of this study is to see how Alzheimer's disease and dementia are misperceived in the media, how this affects audience viewpoints, and how accurate depictions that challenge those stereotypes may or may not change audience perception. Common stereotypes depicted in the media include Alzheimer's and dementia being one disease, only individuals older than 60 years old having this disease, and it being a slow and painful progression towards the end of life. Using Stuart Hall's audience reception theory, I will see if viewers accept, negotiate, or oppose the media that challenges those stereotypes presented to them in contrast to their former knowledge of the disease. Participants took a pre-questionnaire that includes information about their prior knowledge of Alzheimer's and dementia and where they have received that information (from which media platforms and/ or having relatives with the disease). Then they were shown a video depicting characteristics that defy the common stereotypes of Alzheimer's disease and dementia, such as an individual with early on-set Alzheimer's. After which were presented with a post-questionnaire to see if their perception has changed and in what way.

Introduction

In today's society, media plays a significant role in how people interpret information and formulate opinions. Having a well-rounded and full understanding of a topic is important, and the content produced on media channels controls this (Bailey et al 2019, p. 12). Communication and opinions can be heavily influenced by what and how media depicts topics and scenarios. Often times this can cloud audience member's judgment by having a one-sided opinion on a topic. The portrayals of dementia and Alzheimer's disease in the media have common stereotypical depictions including: It only affects older people (age 60 and older), women are more commonly affected by the disease, and people who are diagnosed have anger issues. Other stereotypes also include that it is an end of life diagnosis, and that those who are affected by the disease are very dependent on relatives. Another common misconception is that dementia and Alzheimer's are synonymous, as they are not. Dementia is a general term for memory decline or loss, and Alzheimer's is a specific disease in the brain which accounts for most dementia-related incidents (Zeilig, 2015, P. 15-17).

Moreover, people over the age of 50 may have a better understanding about the disease in comparison to younger generations. This is significant because younger people are more influenced by the media and they do not know the signs of early-onset Alzheimer's or may not even know that there is a possibility they can get it at a young age. Being informed and educated about the truth of this disease, and disproving the stereotypes portrayed in the media, will help those susceptible to identify symptoms of the disease (Hill, 2018, P. 8).

To combat these stereotypes, the language used to describe individuals with Alzheimer's, and the cultural context around it, should be altered to a more accurate representation of the disease. This lack of proper depiction contributes to the negative stigma surrounding the disease

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(Zeilig, 2015, P. 18). The film industry is heavily reliant on stereotypes to "get to the point quicker." According to Capstick et al., (2015), "memory loss, violence and aggression...developing a lack of independency...heavily relying on care of others, a traumatic and devastating prognosis, and ultimately a heartbreaking death" (P. 229) are some of these overused stereotypes depicted in films. In print and news media, the same common stereotypes are used to depict these diseases. Kirkman (2006) analyzed how Alzheimer's was portrayed in print media in New Zealand over the course of a five-year period. Kirkman found that those same stereotypical depictions showed up in a recurring pattern. Kirkman (2006) stated, "The analysis revealed that the media remains a powerful transmitter of stereotypes. In the case of Alzheimer's disease these included those associated with ageing and with dementia" (p. 74). Tonality and key words contribute to the overwhelming misinformed stereotypes associated with Alzheimer's disease.

Media has several types of communicative power that are interpreted differently depending on the audience. Some of these communicative powers can differ "by way of information, by stimulation to action, by directing attention differentially, by persuasion, and by defining situations and framing reality" (McQuail et al., 2020, P. 517). This can cause change due to its large influence over people. Some of the kinds of media-induced change include media being able to cause intended or unintended change, reinforce what may exist, or may even prevent change. The degree for these changes can occur at all levels, from individual to society and culture (McQuail et al., 2020). This is significant to this study as dominant, negotiated and oppositional readers can be influenced by such aspects.

The purpose of this quasi-experimental study will be to test the theory of audience reception that compares whether individuals who have a family member with the disease or not

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have stereotypical perceptions due to references they remember from media. The dominant, negotiate and oppositional reader may or may not be influenced by and have their perception changed due to accurate video depiction of Alzheimer's disease and dementia.

Literature Review

Audience Reception Theory

There are three main reading components that go along with encoding and decoding in the audience reception theory which are dominant, negotiated, and oppositional. Encoding and decoding are the first identifiable parts in the process. These are determinate moments which can be transmitted by any type of media platform. The initial communicative event establishes the message and form being sent to the audience (Hall, 2001). The second part to this is the audience understanding and comprehension as well as perception of the information being transmitted to them. Although the content being presented to the receiver may have a specific intention, the reading response may be consumed and interpreted differently from the originally intended meaning (Hall, 2001).

There are three hypothetical positions in decoding that can occur. "The first hypothetical position is that of the *dominant-hegemonic position*. When the viewer takes the connoted meaning from, say, a television newscast or current affairs programme full and straight, and decodes the message in terms of the reference code in which it has been encoded, we might say that the viewer *is operating inside the dominant code*" (Hall, 2001, P. 171). The dominant reader in these situations understands the message that was intended by the content producers. Another key point to note, "The definition of a hegemonic viewpoint is (a) that it defines within its terms the mental horizon, the universe, of possible meanings, of a whole sector of relations in a society

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or culture; and (b) that it carries with it the stamp of legitimacy – it appears coterminous with what is “natural”, “inevitable”, “taken for granted” about the social order” (Hall, 2001, P. 172).

The second position is the ‘negotiated code’ or position. This position refers to how the audience can see the good and the bad side of the media content even though it may go against their own personal belief, but they accept it because it is a society norm. All audience members have their own unique history and individual experience. Those experiences shape their way of thinking and beliefs in the future. Therefore, members of the audience may challenge the media message presented (Hall, 2001).

The final viewpoint is the ‘oppositional code’. The oppositional reader totally rejects the media message presented to them. This can also be due to their life history and experience which may have shaped their thought process and viewpoints up to the moment of receiving and processing the media message (Hall, 2001).

Hall used the audience reception theory specifically in broadcasting structures and how encoding and decoding aspects transcended into dominant, negotiated and oppositional readers. He looked at the degrees of understand vs. misunderstanding in the intended message of the media and what the audience actually perceived it to be.

In this study, I will be looking at how dominant, negotiated and oppositional viewers respond to found footage that has an accurate representation depicting Alzheimer’s disease and dementia. I will see if their attitude before watching the video may change, stay the same or be refuted after watching the video.

Steven Granelli and Jason Zenor use the reception theory to identify how audiences interpret medical content in the show *Dexter*. The study specifically looks at morality and justice perception depicted in the TV media (Granelli et al., 2016). Granelli and Zeno identify audience

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engagement modes to correlate to the three ideological positions of the theory (dominant, negotiated or oppositional reading). The four audience engagement types are transparent, where the audience reads the “text *as* life”; referential, where the audience reads the “text as *like* life”; mediated, where the audience reads the “text as a *production*”; and discursive, where the audience reads the “text as a *message*” (Granelli et al., 2016, P. 3).

Granelli and Zenor argue that once the individual in the audience interprets the media context as one of those audience interpretation modes, they will then pick the ideological position of dominant, negotiated or oppositional. They found “that there is a clear relationship between a person’s mode of engagement with the text and how they judge the moral actions of the characters, as an audience member’s preexisting frameworks for moral reasoning may lead them to adopt particular modes of reception” (Granelli et al., 2016, P. 19). Granelli and Zenor’s study helped defined Hall’s theory further and expanded on the three audience engagement types.

For purposes of this study, audience reception theory is used to show how the dominant, negotiated and oppositional audiences react after watching a video depicting accurate information about Alzheimer’s disease and dementia. If audience members have had prior experience with the disease and know someone in their family with the Alzheimer’s or dementia, their engagement type may differ. There will be a pre-questionnaire that will see if they believe or agree with the stereotypes commonly referred to in the media. Then participants will view a video which challenges those stereotypes, including content such as a thirty-year-old who has early-onset Alzheimer’s disease.

Following the video viewing, participants will be asked more questions to see how/ if their attitude has changed, stayed the same, or if they refute the information presented to them.

For this study, Hall's theory will be key in seeing after individuals view the video which challenges stereotypes, if they will actually change their opinions on the topic, if they will be somewhat hesitant to change their view but acknowledge the possibility, or if they will completely refuse to accept the contrary information to the stereotypes. I hope to show that people's opinions can change when accurate footage is presented to them. This channel of communication which shows accurate information is key in having a better picture of the topic.

Related Studies

Anna Šestáková and Jana Plichtová explore the representation of Alzheimer's and dementia in Slovak media across multiple media platforms (TV, radio, print and web based sources). The criteria for the study analyzed key words of "Alzheimer" and "dementia" during a four year time span. Their study found that the primary depiction associated with those words were tragic and represented a cruel disease (Šestáková et al., 2019).

A primary gap in this study is the limited keyword search that was used. If more associated, as well as specific words were used in the search, the level of accuracy and a better picture may have been drawn in conclusion from the research.

Elizabeth Peel studied the effects of print media and the depiction of content related to Alzheimer's disease. This study looked at panic and preventative content comparisons in print media, newspapers in particular, over the course of one year. Peel argues that the presence of "individualistic dementia 'preventative' behaviour in media discourse is problematic" (Peel, 2014, P.1), particularly when compared to different treatable chronic conditions. The panic-blame media messages may play an active role in pushing social change for people diagnosed with dementia (Peel, 2014).

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Although Peel identified key behavioral depiction problems, she primarily looked at panic and preventative Alzheimer's content. To expand upon this search, a broader range of Alzheimer's elements depicted in media should have been looked at to get a more well-rounded portrayal.

Andrea Capstick, John Chatwin and Katherine Ludwin study the misrepresentation of dementia in films. They argue that "Representations of people with dementia in film tend to draw heavily on familiar tropes such as global memory loss, violence and aggression, extreme dependency on heroic carers, catastrophic prognosis, and early death" (Capstick et al., 2015, P. 229). In fiction films, many of these stereotypes and misconceptions are displayed to the mass audience in most Alzheimer's blockbuster in the US and UK. Contrary to this, documentaries have shown a more accurate depiction of the disease. Videos that include accurate messages from health care workers and nursing staff, convey a more accurate and reliable perception of Alzheimer's and dementia (Capstick et al., 2015).

Capstick, Chatwin and Ludwin studied several blockbuster films to confirm the problematic representation of individuals with dementia. One specific example of this was in their analysis of the movie *Rise of the Planet of the Apes*, where a character in the film had Alzheimer's disease. His disability showed his loss for memory specifically in playing the piano. Music however, is far less likely to be associated with memory loss in dementia and short term memory (Capstick et al., 2015).

The study continues on to analyze TV soap operas and their depiction of the disease and dementia. Many TV soaps "...suggest... that dementia is a condition that people quickly die from rather than live with and that their prognosis is very poor. To date, there has been a dearth of characters with dementia in TV soaps who continue to appear over a realistic timescale, have

storylines unrelated to their prognosis, or contribute positively to their family and community” (Capstick et al., 2015, P. 237).

There are several key points addressed in this study that further research regarding the misrepresentation of the disease and dementia including but limited to character depiction, genre change and theme of the disease depiction and factual contributions that should be added to films. Something that could have been a useful addition to this study would be to look at supporting character’s role and how they understand the disease. This would show if film depiction of surrounding members of the film have an accurate understanding of the disease or if they too are influenced by stereotypes.

Research Questions

The current research done in the area of media depiction of Alzheimer’s and dementia and the role it plays on peoples perception shows the need for further analysis. By challenging stereotypes due to media manipulation, we can better understand the influence and perceptive roles that the media depicts. My study will attempt to add to present research done and further the understanding about the dominant, negotiated and oppositional audiences in relation to video influence about Alzheimer’s disease and dementia. The following research questions will be further explored:

RQ1: Is there a difference in audience engagement with people who have relatives with Alzheimer’s or dementia vs. people who don’t?

RQ2: Is there a difference in how dominant, negotiated and oppositional audiences respond to accurate depiction of Alzheimer’s and dementia?

Methodology

This quasi-experimental method uses a pre-questionnaire and post-questionnaire with a video separating the two. The pre-questionnaire establishes the participants age and background knowledge of the disease. They were asked if they knew of / are closely related to someone with the disease and if they themselves think they are knowledgeable about the topic. They were then asked to choose which forms of media they have seen Alzheimer's and / or dementia depicted in (i.e. TV, movies, radio, newspaper, etc.). They described to the best of their memory how those characters were depicted and if they believe the representation was accurate. Participants were then asked to identify some common words associated with Alzheimer's disease from a set list, which is later shown again in the post-questionnaire to see if their response changed. The word group included keywords such as sadness, old age, young age, memory, aggression, dependence, care facilities, and so on. This is significant in understanding where the participants background opinions and attitude about the disease may come from, and if it is in a one-sided view of communication.

The participants were then asked to watch a short video which included found footage of characters depicting Alzheimer's disease in an accurate account. Some of the clips include scenes of a young woman being diagnosed with Alzheimer's disease as well as an older woman who has a moment of clarity after her Alzheimer's diagnosis. The purpose of these clips in relation to Hall's theory is to challenge what the participant may have prior knowledge about regarding the disease and see in the post-questionnaire if their opinions have changed, stayed the same or if they completely refute the information that was presented to them.

In the post-questionnaire, participants were asked what if any of their thoughts or prior conceptions of Alzheimer's disease and dementia changed and what if any were reinforced. Then

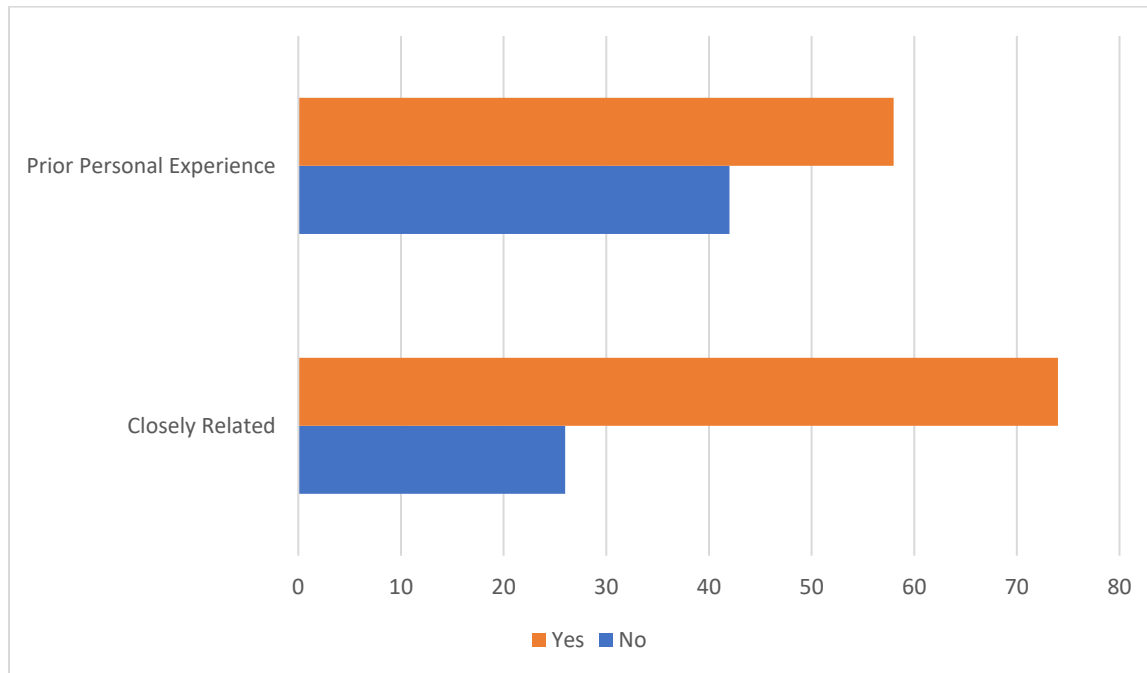
they were asked if their attitude changed, stayed the same or if they do not believe the information in the video in relation to early on-set Alzheimer's, difference between dementia and Alzheimer's disease, the sad emotion commonly depicted with Alzheimer's disease, and dependence for someone who has Alzheimer's disease. The question asked in the pre-questionnaire regarding common words associated with the disease was asked again in the post-questionnaire to see what responses changed.

In relation to the scope of communication as a whole, this method is significant in seeing how a viewer reacts to media representations of certain topics, in this case Alzheimer's disease, and how their attitude may reflect that. Using Hall's theory in relation to this as well, this concept can be tested to see if a viewers attitude may change.

Results

The survey recorded a total of 43 responses with an age range from 22 – 72 years old and the mean age being 43. In the pre-questionnaire, when asked if the participant considers themselves knowledgeable about Alzheimer's disease and / or dementia, approximately 50% answered yes and 50% no. Approximately 58% of participants claimed to have personal experience with Alzheimer's disease and approximately 74% of participants were closely related to someone with dementia. Over 80% of participants knew that Alzheimer's disease and dementia are not the same thing, and 75% of participants knew that Alzheimer's disease can affect people in their 30's.

Table 1: Prior Experiences Groups



The above table shows the percent of participants who answered yes and no to having prior personal experience and / or close personal relations to someone with Alzheimer’s disease and dementia.

When participants were asked where they have seen depictions of the disease and / or dementia, the majority said television shows, followed by movies, commercials, magazines and social media. The least seen and heard media that depicted the disease / dementia was on radio shows and in newspapers. When asked what specific media channels were seen depicting them, participants listed several infomercials about Alzheimer drugs, AARP commercials, movies such as *Still Alice*, *Rise of the Planet of the Apes*, and *Supernova*, shows and stage plays, non-profit organization and support groups on social media, fundraiser podcasts, and news articles about local individuals with the disease. The participants were then asked to describe how those characters / individuals with the Alzheimer’s disease and / or dementia were depicted. The majority of responses included having a sad depiction, being confused and forgetful, having

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older age to the person diagnosed with the disease, being lost and scared, aggressive, a terminal stage, and a loss of independence and dignity. When asked if these participants thought their prior viewing experience was accurate, approximately 55% said yes and 45% said no or felt unsure that the media portrayed the full picture of the disease and dementia.

The final question that was asked in the pre-questionnaire was what common words / phrases participants thought were associated with Alzheimer's disease and dementia. The most common words / phrases were old age, memory, sadness, dependence, and end of life. The least common word / phrase was young age. This question would be asked again after viewing the video.

After watching the video, the participants were asked what if any of their thoughts or prior conceptions of Alzheimer's disease and dementia changed and what if any thoughts or prior conceptions of Alzheimer's disease and dementia were reinforced.

Table 2: Prior thoughts changed and reinforced

Prior thoughts that were changed	Prior thoughts that were reinforced
'It's not a one size fits all, it's not just a disease that older people get'	It is a progressive disease
There is a big literary and grammatical struggle for people diagnosed with the disease	It is related to an individual's memory
A brain scan can help diagnose Alzheimer's disease	Aggression can be a symptom related to the disease
It could potentially be a genetic disease	It is painful for the people around the diagnosed individual
Alzheimer's disease and dementia are separate things	That it could be genetic and mild for a few years
It is not just an end of life disease	Younger people can get it (unaware how young though) and older people can too.
That individuals with the disease can be good at covering up symptoms in the earlier stages	One moment they are fine and the next they can't remember where they are

The above table represents answers from participants regarding what, if any, of their prior thoughts were changed and reinforced.

Participants were then asked if their attitude has changed, stayed the same or if they did not believe the information in the video regarding several topics related Alzheimer's disease and / or dementia. Nearly 41% of participants said their attitude changed after watching the video regarding early on-set Alzheimer's disease. Regarding the difference between Alzheimer's disease and dementia, 68% of participants stated their attitude stayed the same, 27% stated their attitude changed, and 5% stated they did not believe the information. Approximately 32% of participants stated their attitude changed regarding the sad emotions commonly depicted with Alzheimer's disease, and 27% of participants attitude changed regarding the dependence for someone who has dementia or Alzheimer's disease.

The common word association question was repeated again and the new top common word associations were memory, sadness, young age, fearful and women. One of the least common phrase associations was end of life.

*See Appendix for additional participant comments.

Conclusion

This study identified several key aspects in the realm of communication. It is clear that media can be one sided and have a heavy persuasive effect on viewers. Participants who knew someone or were closely related to someone diagnosed with Alzheimer's disease knew more accurate information about the disease and tended to focus on the aggression and agitation surrounding the disease than people who were less knowledge about it and didn't know anyone with the disease. Often times the participants who knew more about the disease easily identified the misconceptions in their prior media experiences and were open to learning more about early

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on-set Alzheimer's disease. Participants who did not know as much about the disease and / or dementia were more focused on the memory and did not know much if anything about early on-set Alzheimer's disease. Participants with little to no personal experience with Alzheimer's disease were more likely to change their opinions after watching the footage than those who had prior experience. This is a representation that people interpret media differently depending on what their prior knowledge is, especially if their prior experiences were one sided.

Moving forward from this, media depiction should accurately represent this disease so that younger generations are not misinformed about what their relatives, or even themselves, may one day go through. Most of the time, movies and shows only depict stereotypes because they are on a time constrain and must get to the point of the story. However, there is a more productive and educational way of doing so if they accurately depict the disease and inform viewers about the true nature of Alzheimer's. Representation of Alzheimer's disease should show that young people can get it, that it is not an immediate end of life sentence and that individuals with the disease can still have moments of clarity. This will limit the amount of inaccurate content, educate audience members, and minimize stereotypes.

This study shows that communication and representation in media can be manipulated and have a heavy impact on the way audience members view topics and perceive information. If audience members are then shown accurate information after having a prior misconception to a topic, they will either accept the new information or refute what is being shown to them. Beyond this specific context of Alzheimer's disease, media representation should have accurate depictions on every topic so that people do not have the wrong impression and then communicate that misinformation to other individuals. Although audience members may change their opinions or prior thoughts, not everyone will and therefore it is important for media to

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represent accurate, factual information from the start. This study adds to the understanding of how media representation can persuade and alter audience members beliefs and thoughts.

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Appendix

Listed below are some additional anonymous comments by participants:

- “It was actually informative. It’s different seeing it thru someone else’s eyes. As I usually only see it thru my own eyes. Due to having the 1st stages of Alzheimer’s myself. I see what it takes out of friends & family who try so hard to help. Each night I try to pray that I have a good day the next day & that they find a cure for the bad days soon !”
- “My 58yr old mother is in late stages of early onset alz. She hits me, punches, tries to bite my father. Screams out in manic torment ALL DAY LONG begging me to give her a gun so she can kill herself. Alzheimer’s is SO MUCH worse than videos show. Personally, I have completely lost my identity in caring for my mother these past 3yrs. I look at pictures and don’t even recognize who I used to be; strong, confident, high achiever, passionate, motivated, a mother, a wife. I am now “a daughter of Alzheimer’s.” I don’t dream about my future anymore, I’ve lost so much of my hair from stress, have stress related lupus rashes all over me, have developed a shaking in my hands, and had shingles on my scalp. sadness and grief overtake all my daily priorities and weigh on my chest like a boulder. ***There must be more awareness about this!! June is Alzheimer’s awareness month— I didn’t see anything posted anywhere, other than all of the rainbows for gay pride month. There’s not 1 single survivor. We NEED a cure.”
- “I have an uncle who passed away at the age of 97 in October. He was diagnosed with dementia about 5 years ago. I watched him go from his normal ornery self to downright mean and abusive to his caregivers. He was in an assisted living facility for 6 years and a nursing home for a year. He got progressively worse, not remembering names, where he was, etc. He didn't remember that his parents and grandparents had passed away and

would cry. I felt compassion for all of the people in the these videos because of how I felt seeing my uncle deteriorate over the years. I would love to learn more about the possibility of preventing the disease in myself and my loved ones.”

- “I am hopeful that additional gains will be made in understanding and finding treatments for all forms of dementia. My wife and I are in our 70's, we just visited my mother-in-law who is in her 90's and sharper than ever. My wife's Dad past in his 70's with dementia, but he was a paratrooper and a race car driver, so several head injuries in his younger years. My mother had mini-strokes during and right after her open heart bi-pass surgery at 85, she past at 87. My Dad was sharp until he past at 87, I like to think, from a broken heart from Mom passing.”