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# **CHANGING THE NARRATIVE - AGING & THE FUTURE OF CARE: STUDY OF THE IMPACT OF *THIS IS US* ALZHEIMER'S STORYLINE**

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## EXECUTIVE SUMMARY

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### Methods

The 4<sup>th</sup> Season of the popular television show *This Is Us* included a storyline about Rebecca's memory decline and a conflict within the family regarding her participation in a clinical trial for Alzheimer's disease. In collaboration with researchers at the University of Pittsburgh, Hollywood, Health & Society conducted an online survey of 720 *This Is Us* viewers using Qualtrics Sampling Services to assess viewers' perceptions of Rebecca's sons, Kevin and Randall, and their divergent plans for their mother's care. The study also examined the influence of the storyline on viewers' behavioral intent towards planning for their own aging. To further explore these topics, we conducted 4 focus groups with 12 participants—all of whom were survey respondents.

We aimed to answer the following three research questions:

RQ1: What are viewers' perceptions of Kevin and Randall and their differing plans for Rebecca?

RQ2: What is the influence of the storyline on viewers' behavioral intent towards planning for aging?

RQ3: Are viewer perceptions of Kevin's and Randall's differing plans for Rebecca and behavioral intent associated with attitudes towards medical research, personal experience related to Alzheimer's disease and caregiving, or socio-demographic characteristics?

### Results

Although we expected that viewers would identify with either the character of Kevin OR the character of Randall, survey participants strongly identified with both. Identification with one character was not correlated solely with agreement with that character's plan for Rebecca, rather, identification with both characters was positively correlated with support for both Kevin's position to respect Rebecca's wishes and Randall's insistence that Rebecca participate in the clinical trial. Consistent with the survey findings, during the focus groups participants mentioned understanding and supporting Kevin's position as well as Randall's. Participants discussed Kevin's approach as "realistic" while Randall's approach was considered "optimistic."

We also found that the storyline had an influence on viewers behavioral intent related to planning for aging. For example, on a scale from 1 (strongly disagree) to 7 (strongly agree) average agreement with the statement "seeing this storyline has made me think about my aging differently" was a 5, and the average agreement with the statement "seeing this storyline has led me to plan for my aging" was a 4.4. Results from the focus groups suggest this influence

may occur through a reduction in stigma, with focus group participants expressing hope that the storyline would highlight how Alzheimer's disease affects the whole family. Participants also spoke favorably about the storyline's depiction of Rebecca's denial with regard to the seriousness of her symptoms and the potential of this depiction to help viewers recognize such symptoms in themselves or loved ones and seek medical attention earlier.

Results from the survey suggest that support for medical research and personal experience with caregiving or having a loved one with a diagnosis of Alzheimer's are both strongly associated with the influence of the storyline on viewers. For example, greater personal experience was associated with greater agreement with the statement "seeing this storyline has led me to discuss plans for my aging with my family" ( $B=0.21, p<0.001$ ). Focus group participants spoke openly about their personal experience caring for a parent with Alzheimer's disease, as well as their support for medical research and clinical trials. Some participants mentioned wishing it would have been possible to have their parent participate in a clinical trial, even if the trial would not benefit the individual directly.

Overall, results from this study suggest that while on screen Kevin's plan for addressing Rebecca's diagnosis is presented at odds with Randall's, viewers' perceptions of these plans are more nuanced. Examining results from both the survey and focus groups together suggests the storyline influenced viewers' behavioral intent related to planning for aging, possibly by reducing stigma and providing a realistic portrayal of the early symptoms of Alzheimer's disease.

## INTRODUCTION

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Even in the rapidly changing entertainment climate of niche cable channels and streaming services, prime time broadcast series continue to attract large audiences, with the most popular shows reaching more than 18.5 million viewers (Santiago, 2017). Exposure to media, and to television in particular, has the potential to cultivate viewers' perceptions of reality over time (Gerbner, Gross, Morgan, Signorielli, & Shanahan, 2002). Additionally, research shows that health-related television storylines, even on non-medical based programs, can influence health outcomes (Gillig, Rosenthal, Murphy, & Folb, 2018; Hoffman, Shensa, Wessel, Hoffman, & Primack, 2017; Yoo & Tian, 2011). Relatively little is known, however, about the influence of storylines depicting dementia and Alzheimer's disease on viewers.

The SCAN Foundation recognizes the impact cultural narratives have on the way individuals think about aging, whether by strengthening patient involvement in health care decisions through a person-centered care approach or promoting the dignity and independence of older adults. This report describes results of a study examining the impact of a storyline from the 2019-2020 season of the popular television program *This Is Us* on viewers' attitudes and behavioral intent related to planning for aging and caring for a loved one with Alzheimer's disease.

### **Alzheimer's Disease**

Dementia is the overall term for a group of disorders characterized by memory loss complications and skill degradation in language, cognition, visual mapping, and problem-solving (Alzheimer's Association, 2020; Kenner, 2008). These symptoms are usually irreversible and progressive, impairing the patient's ability to engage in everyday activities (McKhann et al., 2011). While a variety of disorders show dementia symptoms, Alzheimer's disease is the most common cause, accounting for 60-80% of dementia cases (Alzheimer's Association, 2020). In 2020, an estimated 5.8 million people in the United States (U.S.) were living with dementia (Alzheimer's Association, 2020).

Despite its growing prevalence and economic burden, there is a void in resources and awareness about dementia (Epps et al., 2020; Patterson, 2018). As of today, there is no cure for Alzheimer's disease and related dementias. Clinical trials for medications to treat Alzheimer's disease have had limited success with medications that have demonstrated effectiveness at alleviating symptoms associated with adverse effects (Emre et al., 2004; Khoury, Rajamanickam, & Grossberg, 2018). Current treatment recommends early diagnosis (Matthews et al., 2019), and nonpharmacologic therapies such as aerobic exercise and social engagement have demonstrated the ability to maintain or improve cognition function (Langa & Levine, 2014).

Additionally, about 1.35 million (3.3%) U.S. adults identify themselves as caring for or making health care decisions for someone with Alzheimer's, confusion, dementia, or forgetfulness (National Institutes of Health, 2019). Caregivers often face a significant amount of burden and stress (Cheng, 2017; Chiao, Wu, & Hsiao, 2015), and their decisions often impact how the

patient receives treatment and how the family as a whole provides care. Further complicating matters, loved ones' opinions can sometimes diverge as to what constitutes the optimal treatment option.

Moreover, insufficient awareness and knowledge about dementia correlates to health disparities experienced by disadvantaged communities (Epps et al., 2020; Patterson, 2018). Thus, dementia-related media portrayals on mass communication platforms may be a promising way to increase public awareness and equip audiences with the necessary knowledge to cope with dementia when it occurs to themselves and/or their family members. It may also help viewers consider the importance of making plans for their own aging.

### ***This Is Us***

*This is Us* premiered on NBC in 2016 and follows the lives of the Pearson family, taking place mostly in the present but showing the family's past and future through flashbacks and flash forwards. The show primarily focuses on triplets Kate, Kevin, and Randall, who in present day are in their 30s. In present day the mother, Rebecca, is married to Miguel following the death of her husband Jack when the triplets were 17. Kate and Kevin are two surviving children from a triplet pregnancy, with Randall, who is Black (the rest of the family is White) adopted the same day.

Hollywood, Health & Society has been consulting with the series on an Alzheimer's disease and caregiving storyline as part of the 4th season, which aired its finale on March 24, 2020. The storyline focuses on Rebecca's memory decline and diagnosis of mild cognitive impairment likely due to Alzheimer's disease. It also focuses on conflict within the family with regard to caregiving. Specifically, Kevin and Randall clash over Randall's insistence that Rebecca move to St. Louis to participate in a clinical trial for people with Alzheimer's disease. While originally Rebecca chooses not to participate in the trial she ultimately agrees after Randall's insistence. When Kevin realizes Rebecca changed her mind due to pressure from Randall, the brothers exchange harsh words that result in not speaking for months.

### **Influence of Entertainment Narratives**

Theories explaining the profound impact of entertainment narratives on viewers traditionally focus on two concepts: identification with key characters and transportation into the narrative (Moyer-Gusé, 2008). Per social cognitive theory, when viewers observe a character on television with whom they identify engaging in certain behaviors, they may be prompted to change their own behavior to mirror that of the character. Additionally, the extended-elaboration likelihood model posits that when one is engrossed in an entertainment narrative, attention and cognitive resources are devoted to following the story and characters; this transportation into the fictional world may lead to a lack of counterarguing against the depicted messages, eventually leading to persuasion in line with the messages in the entertainment program (Moyer-Gusé, 2008).

## **Overview of Research**

The current study aimed to systematically analyze perceptions of the *This Is Us* storyline and the influence of the storyline on behavioral intent towards planning for aging. The first portion of the study involved an online survey of 720 U.S. adults who indicated they had viewed the 2019-2020 Season of *This Is Us*. The second portion of the study involved 4 focus groups with 12 participants—all of whom were also survey respondents—to further explore these topics. We aimed to answer the following three research questions:

RQ1: What are viewers' perceptions of Kevin and Randall and their differing plans for Rebecca?

RQ2: What is the influence of the storyline on viewers' behavioral intent towards planning for aging?

RQ3: Are viewer perceptions of Kevin's and Randall's differing plans for Rebecca and behavioral intent associated with attitudes towards medical research, personal experience related to Alzheimer's disease and caregiving, or socio-demographic characteristics?

## METHOD

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### Sample

#### Survey

We used Qualtrics Sampling Services to recruit an online sample of U.S. adults who indicated they had viewed at least one episode of the 2019-2020 season of *This Is Us*. We disseminated the survey at the end of June 2020, approximately 3 months after the airing of the 2019-2020 finale; 720 respondents completed the survey.

#### Focus Groups

At the completion of the survey, respondents were asked to provide an email address if they wished to be contacted for participation in a related focus group. Researchers held a total of 4 focus groups with 12 participants total—all of whom were also survey respondents—from October-November 2020.

### Measures

#### Survey

In consultation with experts in aging research, we developed an online 10-15 minute survey. The survey was pilot tested by individuals familiar with *This Is Us* and entertainment education research.

#### *Research Question 1*

We assessed identification with the characters of Kevin and Randall using items adapted from previous entertainment education studies (Gillig et al., 2018; Murphy, Frank, Moran, & Patnoe-Woodley, 2011). For each character, participants were asked to rate their agreement on a scale of 1 (strongly disagree) to 7 (strongly agree) with 7 statements, such as “I think I have a good understanding of Kevin (or Randall)” and “While viewing the show, I want Kevin (or Randall) to succeed in achieving his goals.” Responses to each item were summed to create an identification variable for both Kevin and Randall, with scores ranging from 7 to 49 and a higher score indicating greater identification with that character.

We assessed viewer perceptions of the Alzheimer’s disease and caregiving storyline through four items asking participants to indicate their agreement with each of Kevin’s and Randall’s plans for Rebecca on a scale from 1 (strongly disagree) to 7 (strongly disagree).

#### *Research Question 2*

We measured storyline influence by asking participants to rate their agreement on the same 7-point scale with six statements such as “seeing this storyline has led me to plan for my aging.” We measured behavioral intent by asking participants to rate their agreement on the 7-point scale with the following two statements: (1) If my relative had Rebecca’s diagnosis, he/she would be able to make his/her own decisions about participating in research and (2) If my relative had Rebecca’s diagnosis, I would be willing to override his/her preferences about participating in research.

### *Research Question 3*

We assessed attitudes towards participating in medical research using the validated research attitudes questionnaire (Rubright, Cary, Karlawish, & Kim, 2011), which contains six items such as “I have a positive view about medical research.” Participants indicated their agreement with each statement on a scale from 1 (strongly disagree) to 7 (strongly agree). Responses to each item were summed, with a higher score (range = 6-35) indicating a higher value placed on medical research.

We assessed participants’ personal experience related to dementia and caregiving by asking 11 yes/no questions such as “A friend or close relative of mine has been previously diagnosed with dementia or Alzheimer’s disease.” Each “no” response was assigned a score of 0 and each “yes” response was assigned a score of 1. We then summed the scores to create a 0-11 scale, with 0 indicating no personal experience and 11 indicating the most personal experience.

Finally, we asked respondents to self-report socio-demographic characteristics such as age in years, gender identity, and race/ethnicity.

### Focus Groups

At the beginning of each focus group, participants viewed a 10-minute clip of scenes from Season 4 related to the Alzheimer’s disease and caregiving storyline. Following this, we asked participants a series of open-ended questions with appropriate probes to explore their (1) understanding of Rebecca’s diagnosis, clinical trials, and both Kevin’s and Randall’s plans for Rebecca, (2) identification with Randall and Kevin, and (3) thoughts on the relationship between personal experience with Alzheimer’s disease or caregiving and influence of the storyline. Prior to the focus groups, questions were pilot tested and refined by the research team and volunteers familiar with the storyline.

Focus groups were conducted using Zoom videoconference software (“Zoom,” n.d.). At the beginning of each focus group the facilitator provided ground rules including respecting participants’ views and allowing equal opportunity for participation. Focus groups were audio recorded for transcription, and the facilitator and a second researcher took handwritten notes during each session. Each focus group discussion lasted approximately one hour.

### **Analysis**

For the survey responses, we answered Research Question 1 by first calculating descriptive statistics (mean and standard deviation) for each item. We then ran bivariate correlations to assess if identification with Kevin was a separate construct than identification with Randall. To answer Research Question 2, we calculated descriptive statistics (mean and standard deviation) for each behavioral intent item. To answer Research Question 3, we created linear regression models to assess associations between viewer perception and behavioral intent items with attitudes towards medical research, personal experience, and participant age, gender, and race/ethnicity. Data were analyzed using Stata Version 15 (StataCorp, 2018).



Audiotape recordings of focus group sessions were transcribed and reviewed for accuracy by two members of the research team. Transcripts were entered into NVivo software for qualitative analysis (QSR International Pty Ltd, 2018). We developed an initial set of thematic codes consistent with the research questions and two researchers, working independently, coded the first focus group transcript, adding and modifying codes based on textual analysis. The researchers then met to discuss their findings and modify the codebook, synthesizing codes into major themes and their related sub-themes. We codified a final codebook, and all four focus group transcripts were independently double-coded using this codebook. Double-coding not only served as a form of quality control but also allowed for investigator triangulation, whereby at least two researchers independently read the text to identify emergent themes (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014; Patton, 1998).

## RESULTS

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### Sample Characteristics

The majority of survey participants were 18-44 years of age (54.3%) and identified as Female (66.5%). With regard to race/ethnicity, 80.1% of participants identified as White or Caucasian, mirroring Nielsen data suggesting 89% of This Is Us viewers are not Black (Nielsen, 2017). Complete results are presented in **TABLE 1**. The majority of focus group participants (75%, n=9) identified as Female (e.g. used she/her pronouns), with 10 (83.3%) 50+ years of age.

**TABLE 1. Respondent Characteristics (N=720)**

Socio-Demographic Characteristic	Frequency	Percent
<b>Age</b>		
18-24	73	10.1
25-34	143	19.9
35-44	175	24.3
44-54	97	13.5
55-64	116	16.1
65+	116	16.1
<b>Gender</b>		
Male	236	32.8
Female	479	66.5
Transgender or Non-binary	3	0.4
Prefer Not to Answer	2	0.3
<b>Race and Ethnicity</b>		
White or Caucasian	581	80.1
Hispanic or Latinx	48	6.7
Black or African-American	53	7.4
Other	55	7.5
Prefer Not to Answer	4	0.6

### Research Question 1

Survey responses indicated that viewers strongly identified with both Randall and Kevin; median identification score was the same for both characters (median=37, IQR=31-42). Additionally, there was a strong positive correlation between identification with Kevin and identification with Randall ( $r=0.7$ ,  $p<0.01$ ).

Quantitatively, identification with both characters was positively correlated with support for both character's plans for Rebecca. Please see **TABLE 2** for means, standard deviations, and bivariate correlations for all identification and viewer perception items.

**TABLE 2. Means, Standard Deviations, and Bivariate Correlations (N=720)**

	M	SD	1	2	3	4	5	6
Identification with Kevin (1) <sup>a</sup>	36.2	8.1	1.0					
Identification with Randall (2) <sup>a</sup>	35.9	8.4	0.74**	1.0				
Kevin's desire to respect Rebecca's wishes to not participate in the clinical trial (3) <sup>b</sup>	5.0	1.4	0.50**	0.30**	1.0			
Randall's insistence that Rebecca participate in the clinical trial (4) <sup>b</sup>	4.3	1.5	0.34**	0.49**	0.03	1.0		
The family should let Rebecca make the final decision about what she wants to do regarding the clinical trial (5) <sup>b</sup>	5.4	1.4	0.37**	0.22**	0.50**	-0.08*	1.0	
The family should do whatever it takes to help Rebecca regardless of her wishes (6) <sup>b</sup>	4.3	1.7	0.22**	0.30**	0.03	0.47**	-0.12*	1.0

<sup>a</sup> Measured on a scale from 7 to 49, with a higher score indicating more identification

<sup>b</sup> Measured on a scale from 1 (strongly disagree) to 7 (strongly agree)

\*  $p<0.05$  \*\*  $p<0.01$

Consistent with the survey findings, during the focus groups participants mentioned understanding and supporting both Kevin's and Randall's positions. Participants discussed

Kevin's approach as "realistic" while Randall's approach was considered "optimistic" or "hopeful." Participants remarked that these approaches were not necessarily in opposition, as exemplified by the following quote from a participant in the first focus group:

*"I think it's human nature, to have that dichotomy, especially in a stressful situation, you know, with your parent who you love dearly, you know, part of you wants to say, this is going to help, but the other part of you goes 'no, there is no way to come out of this.' So, I think that's just really human nature to have that dichotomy in your brain about which way is the best way to go, because in fact, no one knows which way is the best way to go."*

The majority of participants noted they are "more like Randall" or "am the Randall of the family." Participants mentioned relating to Randall's insistence on getting his mother medical care and gathering information about her condition, but noted they would not override their loved one's decision and would not want their loved one to be far away from family as Randall's plan would require.

## Research Question 2

Participants indicated moderate agreement with the six statements assessing influence of the storyline on their perceptions of aging, plans to discuss aging with their family, and likeliness to participate in a clinical trial (TABLE 3).

**TABLE 3. Mean Score and Standard Deviation for Items Assessing Storyline Influence and Behavioral Intent**

Statement	Mean* (SD)
Seeing this storyline has made me think about my aging differently	5.0 (1.5)
Seeing this storyline has led me to plan for my aging	4.4 (1.6)
Seeing this storyline has led me to discuss plans for my aging with my family	4.3 (1.8)
Seeing this storyline has led me to discuss plans for a family member's aging with my family	4.3 (1.8)
Seeing this storyline has made me MORE likely to participate in a clinical trial if I were to receive Rebecca's diagnosis	4.6 (1.6)
Seeing this storyline has made me MORE likely to want a loved one to participate in a clinical trial if he/she were to receive Rebecca's diagnosis	4.6 (1.6)
If my relative had Rebecca's diagnosis, he/she would be able to make his/her own decisions about participating in research	5.1 (1.5)
If my relative had Rebecca's diagnosis, I would be willing to override his/her preferences about participating in research	4.0 (1.6)

\* On a scale from 1 (strongly disagree) to 7 (strongly agree)

Focus group participants did not mention a direct influence of the storyline on their behavioral intent, but several themes emerged as to how participants felt the storyline could influence viewer behavior. One theme that emerged was Rebecca and her husband's denial about the severity of her symptoms. Participants felt this was a realistic portrayal of the denial common to people experiencing early symptoms and expressed hope that the storyline would make viewers more willing to admit a problem and seek medical care earlier in the disease course. Similarly, participants felt the storyline could help viewers recognize similar symptoms among loved ones. To quote one participant, "I actually think the show will...open the eyes to people that maybe don't know enough to recognize that those are the early signs of Alzheimer's."

Another theme that emerged during the focus groups was the potential for the storyline to reduce stigma, which in turn could lead to more direct dialogue among family members about treatment options and quality of life. All focus group participants had personal experience with a loved one having Alzheimer's disease or dementia and did not feel the storyline provided them with new information or a new outlook. However, they felt that it could be informative to those without personal experience and could prompt them to plan for future care. As one participant said, "I think it encourages family discussion and it takes away some of the [stigma] of even saying the word Alzheimer's in relationship to a family member."

Finally, focus group participants felt that the disagreement between Kevin and Randall over Rebecca's care would encourage family discussion about care preferences. Participants also extended this to discussions about legal aspects related to dementia and aging, such as medical power of attorney. As one participant explained:

*"I think it gives [viewers] an example of what family issues can...they had tension because they weren't all together on how they should proceed. So, I think it showed some family dynamics and what issues can come up with an ill family member."*

### **Research Question 3**

Survey participants indicated high levels of support for medical research (mean= 31.1, SD= 6.3; median=32, IQR=27-36, scale from 6-36). Attitudes towards medical research was the only predictor variable to be statistically significantly associated with all perception and behavioral intent outcome variables (see **Appendix A** for complete linear regression results), and had the strongest positive association with the statement "Seeing this storyline has made me MORE likely to participate in a clinical trial if I were to receive Rebecca's diagnosis" ( $B=0.12$ ,  $p<0.001$ ).

On a scale from 0-11, median personal experience of survey participants was 1 (IQR=0-2], with 78.9% of participants scoring a 2 or lower. The most frequent personal experience was having a friend or close relative that had been previously diagnosed with dementia or Alzheimer's disease (43.3%,  $n=312$ ). Personal experience was significantly positively associated with agreement with Randall's insistence that Rebecca participate in the clinical trial ( $B=0.11$ ,  $p=0.002$ ) and behavioral intent to think about one's own aging differently ( $B=0.10$ ,  $p=0.006$ ), plan for one's aging ( $B=0.16$ ,  $p<0.001$ ), discuss plans for one's aging with one's family ( $B=0.21$ ,

$p < 0.001$ ), discuss plans for a family member's aging with one's family ( $B = 0.21$ ,  $p < 0.001$ ), participate in a clinical trial ( $B = 0.14$ ,  $p < 0.001$ ), and want a loved one to participate in a clinical trial ( $B = 0.17$ ,  $p < 0.001$ ; **Appendix A**).

With regard to socio-demographic variables, male gender was significantly positively associated with agreement with Randall's insistence that Rebecca participate in the clinical trial ( $B = 0.44$ ,  $p < 0.001$ ). Male gender was also significantly positively associated with behavioral intent to plan for one's aging ( $B = 0.33$ ,  $p = 0.003$ ), discuss plans for one's aging with one's family ( $B = 0.39$ ,  $p = 0.001$ ), and discuss plans for a family member's aging with one's family ( $B = 0.31$ ,  $p = 0.013$ ). Male gender was also associated with behavioral intent to participate in a clinical trial ( $B = 0.28$ ,  $p = 0.007$ ), want a loved one to participate in a clinical trial ( $B = 0.34$ ,  $p = 0.001$ ), and be willing to override a relative's preferences about participating in research ( $B = 0.59$ ,  $p < 0.001$ ; **Appendix A**).

All focus group participants reported some type of personal experience related to Alzheimer's disease or dementia and caregiving, with most speaking openly about having a parent with Alzheimer's disease. When discussing personal experience, particularly with a parent, participants described the progression of the disease as slow and painful. Several participants noted that their loved one's symptoms started off similar to Rebecca's (e.g. losing a phone), but then got progressively worse to the point where the loved one had to enter a memory care facility or nursing home. Participants discussed how the decision to place a family member in a care facility was often a result of the loved one becoming mean and violent. Additionally, several participants described being the primary caregiver for a parent with Alzheimer's, which they noted was "24/7, all encompassing" even if their parent was in a care facility.

In keeping with the survey results, most participants expressed support for Rebecca's participation in the clinical trial and noted they would have wanted their loved one to do the same. For example, one participant said, "if I came across someone in Rebecca's situation like that, I would definitely promote a clinical trial." However, participants felt that Randall's description of the trial as being able to save Rebecca's life was misguided, noting that a clinical trial for Alzheimer's disease is more likely to help future patients as opposed to the patients themselves. As one participant explained, "with my actual personal experience, I believe that it wouldn't necessarily save her [Rebecca] or even necessarily help her. But I do think that it would be in her best interest...to help those in the future."

Further in keeping with the survey results, focus group participants expressed a strong support for clinical research more broadly. The following two quotes exemplify themes discussed by participants related to clinical trials:

*"I'm a strong advocate, a strong believer, and I've met a lot of the doctors that do these clinical trials. And almost without exception, they're heroes, because they put their heart, their soul, their brain, everything into it."*

*"I look at all these clinical trials really, really optimistically....and I think if you know what the outcome is going to be with doing nothing [for Alzheimer's], then*

*you really need to put yourself out there for the opportunity to learn and to maybe help somebody else in the future.”*

However, participants did express concern about participating in a clinical trial that required moving away from loved ones, as was the case for Rebecca. For example, one participant said “I don't want to be away from family for nine months, while my brain is likely getting worse, just to benefit science” while another said “I think it'd be a risk. Not sure I would send my mom.”

## DISCUSSION

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This report provides a resource to understand perceptions of the *This Is Us* storyline about Rebecca's Alzheimer's disease diagnosis, Kevin's and Randall's divergent care plans for her, and the potential influence of this storyline on viewers' perceptions and behavioral intent. Results from both the survey and focus groups suggest the storyline may be a promising way to change perceptions and behaviors related to aging, dementia, and caregiving.

Although we expected that survey participants would identify with either the character of Kevin OR the character of Randall, we found that participants who identified strongly with Kevin also identified strongly with Randall. We also found that identifying more strongly with Kevin was associated not only with agreeing with Kevin's desire to respect Rebecca's wishes, but also with agreeing with Randall's insistence that Rebecca participate in the clinical trial. Similarly, during the focus groups participants mentioned understanding and supporting both Kevin's and Randall's positions. Specifically, participants related to Randall gathering information and insisting Rebecca seek medical care while also relating to Kevin's desire to keep Rebecca close to family. Thus, while on screen the two sons' plans for addressing Rebecca's diagnosis are presented as at odds with each other, our analysis suggests that viewers' perceptions of these plans are more nuanced.

With regard to behavioral intent, triangulation of survey and focus group results suggests that influence of the storyline on viewers' behavioral intent may occur through both helping viewers identify early symptoms and reducing stigma. For example, viewers may be motivated to discuss plans for aging with their family because the storyline portrayed reduced stigma around these discussions and/or due to seeing the tensions that resulted from the disagreement between Kevin and Randall over Rebecca's care. Future research could explore the potential for clips from this storyline to serve as an intervention tool aimed at reducing stigma, increasing awareness of early symptoms of Alzheimer's disease, and promoting care planning discussions.

Although prior research suggests that men are less likely to both be caregivers for relatives with dementia and make medical decisions for family members (Alzheimer's Association, 2020; Wentz-Graff, 2017), our results imply a higher willingness of men to override a loved one with dementia's preferences about participating in a clinical trial compared to women. This may reflect prior findings that men are more likely to engage in behavior aimed at fixing a medical problem, whereas women are more likely to engage in discussion (Wentz-Graff, 2017). Future research could aim to identify the mediating variables through which gender influences attitudes and behavioral intents about aging and dementia caregiving.

Our survey also found that support for medical research was statistically significantly associated with all perception and behavioral intent outcome variables. Although we expected that support for medical research would be positively associated with Randall's insistence that Rebecca participate in the clinical trial, we were surprised to find support for medical research was also positively associated with Kevin's desire to respect Rebecca's wishes to not participate



in the clinical trial. Themes identified during the focus groups related to medical research and clinical trial participation suggest this finding may be due to participants' recognition that a clinical trial for Alzheimer's disease is more likely to help future patients as opposed to Rebecca (or any participant) herself, and participants indicating support for clinical research involvement but not at the expense of relocating away from family.

With regard to personal experience, roughly half the sample of survey participants and all focus group participants had a friend or close relative that had been previously diagnosed with dementia or Alzheimer's disease. Moreover, while greater personal experience for survey participants was statistically significantly associated with agreement with Randall's insistence that Rebecca participate in the clinical trial, it was not associated with agreement with Kevin's desire to respect Rebecca's wishes. Surrogate decision-making, as well as shared decision making, is more common in the context of dementia than in other chronic diseases (Wolfs et al., 2012). As dementia typically progresses fast, not only the primary caregivers but also other family members of a person with dementia may participate in joint decision-making. Although no focus group participants explicitly mentioned overriding a parent's caregiving wishes, many discussed having to make the decision to place a parent in a nursing home or memory care unit, often after their parent became violent. Triangulating results from the survey and focus groups suggests that those with personal caregiving experience may identify with an adult child's decision to override his/her parent's caregiving wishes due to their own experience making difficult caregiving decisions as Alzheimer's disease progresses.

Overall, themes identified during the focus groups related to personal experience, perceptions of medical research and clinical trials, and influence of the storyline on behavioral intent suggest these relationships are complex and multifactorial. For example, focus group participants who expressed support for Rebecca's participation in the clinical trial also felt that Randall's description of the trial as being able to save Rebecca's life was misguided. Similarly, participants expressed support for Rebecca's participation in the clinical trial, while also expressing concern about participating in a clinical trial that required moving away from loved ones, as required for Rebecca. These findings suggest the importance of using qualitative methods to further explore associations garnered from survey research and support the value of mixed-methods studies when exploring the influence of entertainment narratives on health-related outcomes.

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## APPENDIX A

### Associations Between Attitudes Towards Medical Research, Personal Experience, and Socio-Demographic Characteristics with Perceptions of the Storyline and Behavioral Intention (n=720)

	Beta	SE	p
Kevin's desire to respect Rebecca's wishes to not participate in the clinical trial			
Medical Research	0.064	0.008	<0.001
Experience	0.010	0.034	0.770
Age	0.001	0.003	0.769
Gender	-0.095	0.107	0.367
Race	-0.046	0.081	0.569
Adjusted R <sup>2</sup>	0.08		
Randall's insistence that Rebecca participate in the clinical trial			
Medical Research	0.089	0.008	<0.001
Experience	0.109	0.034	0.002
Age	-0.002	0.003	0.636
Gender	0.44	0.108	<0.001
Race	0.041	0.082	0.615
Adjusted R <sup>2</sup>	0.19		
The family should let Rebecca make the final decision about what she wants to do regarding the clinical trial			
Medical Research	0.051	0.008	<0.001
Experience	-0.040	0.033	0.252
Age	0.005	0.003	0.162
Gender	-0.175	0.109	0.106
Race	0.057	0.083	0.495
Adjusted R <sup>2</sup>	0.05		
The family should do whatever it takes to help Rebecca regardless of her wishes			
Medical Research	0.066	0.010	<0.001
Experience	0.108	0.039	0.006
Age	-0.003	0.004	0.503
Gender	0.602	0.123	<0.001
Race	0.108	0.093	0.239
Adjusted R <sup>2</sup>	0.12		
Seeing this storyline has made me think about my aging differently			
Medical Research	0.110	0.008	<0.001
Experience	0.104	0.033	0.002
Age	-0.009	0.003	0.005
Gender	-0.098	0.103	0.335
Race	0.032	0.078	0.679
Adjusted R <sup>2</sup>	0.23		
Seeing this storyline has led me to plan for my aging			
Medical Research	0.092	0.009	<0.001
Experience	0.162	0.036	<0.001
Age	-0.098	0.003	0.335
Gender	0.333	0.112	0.003
Race	0.047	0.085	0.577
Adjusted R <sup>2</sup>	0.20		
Seeing this storyline has led me to discuss plans for my aging with my family			
Medical Research	0.099	0.010	<0.001

Experience	0.207	0.039	<0.001
Age	-0.003	0.004	0.428
Gender	0.389	0.123	0.001
Race	0.089	0.093	0.343
Adjusted R <sup>2</sup>	0.19		
Seeing this storyline has led me to discuss plans for a family member's aging with my family			
Medical Research	0.097	0.010	<0.001
Experience	0.207	0.039	<0.001
Age	-0.015	0.004	<0.001
Gender	0.306	0.124	0.013
Race	0.043	0.094	0.650
Adjusted R <sup>2</sup>	0.20		
Seeing this storyline has made me MORE likely to participate in a clinical trial if I were to receive Rebecca's diagnosis			
Medical Research	0.134	0.008	<0.001
Experience	0.138	0.033	<0.001
Age	-0.000	0.003	0.938
Gender	0.283	0.105	0.007
Race	-0.067	0.080	0.399
Adjusted R <sup>2</sup>	0.32		
Seeing this storyline has made me MORE likely to participate in a clinical trial if I were to receive Rebecca's diagnosis			
Medical Research	0.117	0.008	<0.001
Experience	0.165	0.034	<0.001
Age	-0.005	0.003	0.147
Gender	0.343	0.108	0.001
Race	-0.109	0.081	0.182
Adjusted R <sup>2</sup>	0.28		
If my relative had Rebecca's diagnosis, he/she would be able to make his/her own decisions about participating in research			
Medical Research	0.069	0.008	<0.001
Experience	-0.010	0.034	0.769
Age	-0.004	0.003	0.189
Gender	0.019	0.110	0.864
Race	-0.085	0.083	0.308
Adjusted R <sup>2</sup>	0.08		
If my relative had Rebecca's diagnosis, I would be willing to override his/her preferences about participating in research			
Medical Research	0.078	0.009	<0.001
Experience	0.076	0.037	0.041
Age	-0.009	0.004	0.011
Gender	0.590	0.116	<0.001
Race	-0.109	0.088	0.218
Adjusted R <sup>2</sup>	0.16		