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"It Encourages Family Discussion": A Mixed-Methods Examination of the *This Is Us* Alzheimer's Disease & Caregiving Storyline

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The average United States (U.S.) adult spends approximately one hour interacting directly with a healthcare professional but 2,000 hours watching primetime television annually. Thus, television storylines may be a powerful vehicle for promoting awareness about Alzheimer's disease and caregiving, which affect an estimated 9 million U.S. adults. We used a mixed-methods approach consisting of an online survey of U.S. adult *This Is Us* viewers (n = 720) and 4 focus groups (n = 12) with a subset of survey respondents to systematically assess viewer perceptions of an Alzheimer's disease and caregiving storyline from the *This Is Us* television show and the storyline's influence on viewer behavioral intent toward planning for aging. Triangulation of survey and focus group results suggests the storyline may motivate viewers to discuss plans for aging with their family because of a reduction in stigma and seeing on-screen family tensions related to senior care. Results suggest investments in collaborative partnerships between public health and the entertainment industry may be a valuable way to positively impact those affected by Alzheimer's disease and caregiving. Clips from this storyline could also be used as part of health communication campaigns to encourage advanced care planning discussions.

Background

Even in the rapidly changing entertainment climate of niche cable channels and streaming services, primetime broadcast series continue to attract large audiences (Santiago, 2017). Furthermore, the average United States (U.S.) adult spends only approximately one hour interacting directly with a healthcare professional compared to 2,000 hours watching primetime television annually (Nielsen Media Company, 2018). Consistent with Fisher's narrative paradigm and cultivation theory, this vast exposure has the potential to influence health-related outcomes (Fisher, 2009; Gerbner, Gross, Morgan, Signorielli, & Shanahan, 2002; Gillig, Rosenthal, Murphy, & Folb, 2018a; Hoffman, Shensa, Wessel, Hoffman, & Primack, 2017; Yoo & Tian, 2011). While several films and television storylines (e.g. Still Alice, Iris, Grey's Anatomy) have depicted Alzheimer's disease and caregiving, relatively little is known about the influence of such storylines on viewers.

Alzheimer's Disease

Dementia is the overall term for a group of disorders characterized by memory loss complications and skill degradation in language, cognition, 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, accounting for 60–80% of cases (Alzheimer's Association, 2020). In 2020, an estimated 5.8 million people in the U.S. were living with dementia (Alzheimer's Association, 2020).

In addition to negative patient-level effects, Alzheimer's disease and related dementias are associated with negative interpersonal stressors. According to a 2018 study, approximately 3.2 million U.S. adults provided 4.1 billion hours of unpaid, informal care for family or friends with dementia (Rabarison et al., 2018). These caregivers often face a significant amount of stress (Cheng, 2017), particularly since loved ones' opinions can sometimes diverge as to optimal treatment options. For example, siblings may disagree as to the severity of dementia symptoms exhibited by a parent and whether to move the parent to assisted living or keep him/her at home (Raymond et al., 2014).

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This Is Us Alzheimer's Storyline

The 4th season (2019–2020) of the popular television series *This Is Us* featured a storyline on Alzheimer's disease and caregiving. Briefly, the series follows the lives of the Pearson family, primarily focusing on the mother Rebecca and her triplets Kate, Kevin, and Randall.

Developed in consultation with Hollywood, Health & Society (Hollywood Health & Society, 2021), the storyline focused on Rebecca's memory decline and diagnosis of mild cognitive impairment likely due to Alzheimer's disease. It also focused on conflict within the family regarding caregiving. Specifically, Kevin and Randall clashed over Randall's insistence that Rebecca move cross-country to participate in a clinical trial for people with Alzheimer's disease after Rebecca originally decides against participating. In keeping with prior research demonstrating an association between character identification and the influence of entertainment narratives (Cohen, 2001; Moyer-Gusé, 2008), we hypothesized that:

Hypothesis 1: Greater identification with the character of Kevin will be associated with stronger support for his plan for Rebecca, and greater identification with the character of Randall will be associated with stronger support for his plan for Rebecca.

Conceptual Framework

Given studies suggesting the applicability of the Theory of Planned Behavior (TPB) when examining health communication campaigns and entertainment education (Anderson, Noar, & Rogers, 2013; Bae & Kang, 2008), our conceptual framework is rooted in the TPB (Figure 1). Briefly, the TPB states that behavioral intent is the best predictor of behavior and that behavioral intent is determined by subjective norms (i.e. normative beliefs, motivation to comply with expectations), personal attitude (i.e. behavioral beliefs, evaluation of behavioral outcomes), and perceived behavioral control (i.e. ease or difficulty of performing the behavior) (Montaño & Kasprzyk, 2008). Thus, we assessed viewer perceptions of the storyline and influence of the storyline on viewers' behavioral intent 383

toward planning for aging to assess the potential influence of the storyline on the behavior of planning for aging (Figure 1).

With regard to perceived behavioral control, prior research suggests that self-efficacy and controllability are two constructs within the overarching construct of perceived behavioral control (Ajzen, 2002). Since theories of narrative influence posit that when viewers identify with a character on television they may be prompted to engage in similar behaviors due in part to increases in self-efficacy (Moyer-Gusé, 2008), our conceptual framework incorporates character identification as contributing to perceived behavioral control (Figure 1). Our conceptual framework also acknowledges that, although not explored in this study, structural barriers such as financial resources and home ownership may affect perceived behavioral control (Preston, Drydakis, Forwood, Hughes, & Meads, 2019).

Additionally, our conceptual framework incorporates personal experience related to dementia and caregiving, including life history with a person diagnosed with dementia, as prior research suggests such experience may be associated with behavioral intent toward planning for aging (Kermel Schiffman & Werner, 2021; Sussman, Pimienta, & Hayward, 2021). Finally, given the storyline's focus on participation in a clinical trial, attitudes toward medical research are also a component of our conceptual framework (Figure 1).

Research Design

We designed the current study to systematically analyze perceptions of the storyline, including Kevin's and Randall's plans for Rebecca, and its influence on viewer behavioral intent toward planning for aging and discussing plans for aging with family. The first portion of the study involved an online survey of U.S. adult *This Is Us* viewers. The second portion of the study included four focus groups with a subset of survey respondents to further explore these topics. Related to **H1** and our conceptual framework, we aimed to answer the following research questions:

RQ1: What are viewers' perceptions of Kevin and Randall's differing plans for Rebecca and what is the influence of the storyline on viewers' behavioral intent toward planning for aging?



RQ2: How are viewers' perceptions and storyline influence associated with attitudes toward medical research, personal experience related to Alzheimer's disease and caregiving, and socio-demographic characteristics?

Methods

Sample Selection

We used Qualtrics Sampling Services to recruit an online sample of U.S. adults. Qualtrics disseminated the survey to panel members via e-mail at the end of June 2020. Respondents who indicated they had viewed at least one episode of *This Is Us* Season four were able to complete the survey. Those who completed the survey received points from Qualtrics that could be redeemed in a variety of ways, including gift cards or charitable contributions. To enhance quality of responses, we employed several checks for speeding and accuracy (e.g. failing our attention check asking respondents to choose the answer five in the middle of a question matrix). Qualtrics continued to recruit until we received 720 completed surveys that satisfied speeding and accuracy checks.

At the completion of the survey, respondents were asked to provide an e-mail address if they wished to be contacted for participation in a related focus group. We collected respondent e-mail addresses until we obtained 100. Of the 100 e-mail addresses obtained, 95 were valid and 15 of the 95 responded positively to an e-mail from the lead author about participating. Three of the 15 did not respond to further e-mails about scheduling, leaving a final sample of 12 focus group participants all of whom were also survey respondents. Researchers held a total of four small focus group discussions with these individuals from October-November 2020. This study was approved by The University of Pittsburgh and University of Southern California Institutional Review Boards.

Measures

In consultation with two academic experts in aging research, we developed a brief online survey. The survey was pilot tested by individuals from the authors' institutions familiar with *This Is Us* and entertainment education research.

Identification

We assessed identification with the characters of Kevin and Randall using items adapted from previous entertainment education studies (Gillig et al., 2018a; Murphy, Frank, Moran, & Patnoe-Woodley, 2011). For each character, we asked respondents to rate their agreement with seven items on a Likert-scale of one (strongly disagree) to seven (strongly agree). Example items included "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" (Randall: $\alpha = 0.93$; Kevin: $\alpha = 0.93$). Responses to each item were summed to create an identification variable for both Kevin and Randall, with a higher score indicating greater identification with that character.

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Personal Experience and Attitudes Toward Medical Research We assessed respondents' personal experience related to dementia and caregiving with 11 yes/no items such as "A friend or close relative of mine has been previously diagnosed with dementia or Alzheimer's disease" (Appendix A). We assigned each "no" response a score of zero and each "yes" response was a score of one. We then summed the scores to create a 0–11 scale, with zero indicating no personal experience and 11 indicating the most personal experience.

We assessed attitudes toward 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." Respondents indicated their agreement with each statement on a scale from one (strongly disagree) to seven (strongly agree) ($\alpha = 0.86$). Responses to each item were summed, with a higher score (range = 6–35) indicating a higher value placed on medical research.

Perception and Influence of the Storyline

We assessed viewer perceptions of the Alzheimer's disease and caregiving storyline through four items that asked respondents to indicate their agreement with each of Kevin's and Randall's plans for Rebecca on a scale from one (strongly disagree) to seven (strongly disagree).

We assessed influence of the storyline on viewers' behavioral intent toward planning for aging by asking respondents to rate their agreement on the same 7-point scale with six items such as "seeing this storyline has led me to plan for my aging." Please see Appendix A for a full list of questions related to this construct. An exploratory factor analysis using the maximum likelihood method with oblique rotation identified a single factor with Eigenvalue greater than one, and the single factor explained 90.3% of the common variance of the 6-item scale ($\alpha = 0.90$). Thus, we created a storyline influence variable that was the average of the summed responses to these items (scale from 1–7), with a higher score indicating greater influence of the storyline on viewers' behavioral intent toward planning for aging.

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

Focus Groups

At the beginning of each focus group, participants viewed a 10minute clip of scenes compiled by the research team to refresh their memories about the 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 and (2) identification with Randall and Kevin. Prior to the focus groups, questions were pilot tested and refined by the research team and individuals from [redacted for blind review] familiar with the storyline.

Focus groups were conducted using Zoom videoconference software (Zoom, n.d.). Focus groups were audio recorded for transcription using Zoom, 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 assessed H1 and answered RQ1 by calculating descriptive statistics (mean and standard deviation) for each item and bivariable correlations to assess if identification with Kevin was a separate construct from identification with Randall. To answer RQ2, we created linear regression models to assess associations between viewer perception items and the storyline influence variable (dependent variables), and identification, attitudes toward medical research, personal experience, and participant age, gender, and race/ethnicity. Given the high correlation between identification with Randall and identification with Kevin, prior to running linear regression models we summed scores from both items to create a single identification variable. We analyzed data using Stata Version 16 (StataCorp, 2020).

Audio recordings of focus group sessions were transcribed and reviewed for accuracy by two members of the research team. We developed an initial set of thematic codes consistent with the research questions. Transcripts were entered into NVivo software for qualitative analysis (QSR International Pty Ltd, 2018), and two independent-working researchers coded the first 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 (Patton, 1998). We codified a final codebook, and all four focus group transcripts were independently double-coded.

Finally, we triangulated findings from the focus groups with the survey results to conduct a comprehensive mixed-methods analysis (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Specifically, we examined ways in which the findings from both sources related to each other and where themes uncovered in the focus groups provided insight into associations observed in the quantitative results.

Results

Sample Characteristics

Most survey respondents were 18–44 years of age (54.3%) and identified as Female (66.5%). Approximately 80% of participants identified as White or Caucasian, mirroring Nielsen data on race/ethnicity of *This Is Us* viewers (Nielsen, 2017) (Table 1). The majority of focus group participants (75%, n = 9) identified as female (e.g used she/her pronouns), with ten participants (83.3%) being 50+ years of age.

Research Question 1

Survey responses indicated that viewers strongly identified with both Randall and Kevin (for both characters median = 37, IQR = 31–42). Overall storyline influence was moderate (median = 4.7, IQR = 1–7). There was a strong positive correlation between identification with Kevin and identification with Randall (r = 0.7, p < .01). Identification with both characters was positively correlated with support for both character's plans for Rebecca and storyline influence (Table 2). Thus, H1 was not supported, as rather than identifying with one character and

Table 1. Survey respondent characteristics (N = 720)

Socio-Demographic Characteristic	Frequency	Percent	
Age			
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	
Gender			
Male	236	32.8	
Female	479	66.5	
Transgender or Non-binary	3	0.4	
Prefer Not to Answer	2	0.3	
Race and Ethnicity			
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	

supporting his plan for Rebecca, respondents who identified with one character identified with the other, and supported both characters plans.

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." Participants remarked that these approaches were not necessarily in opposition, as exemplified by the following participant quote:

"With your parent ... 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." (Female, 54 years old)

Most participants noted they are "more like Randall" and related to his insistence on gathering information about Rebecca's condition, but that they would not override their loved one's decision about clinical trial participation

Focus group participants did not mention a direct influence of the storyline on their personal behavioral intent, but several themes emerged as to how participants felt the storyline could influence viewer behavior. One theme was Rebecca and her husband's denial about the severity of her symptoms. Participants felt this was a realistic portrayal and expressed hope that the storyline would make viewers more willing to admit a problem and seek medical care earlier. Similarly, participants felt the storyline could help viewers recognize 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." (Male, 55 years old)

Table 2. Means (M),	standard deviations	(SD), and bivariate	correlations ($N = 720$)
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	М	SD	1	2	3	4	5	6	7
Identification with Kevin (1) ^a	36.2	8.1	1.0						
Identification with Randall (2) ^a	35.9	8.4	0.7**	1.0					
Kevin's desire to respect Rebecca's wishes to not participate in the clinical trial (3) ^b	5.0	1.4	0.5**	0.3**	1.0				
Randall's insistence that Rebecca participate in the clinical trial (4) ^b	4.3	1.5	0.3**	0.5**	0.03	1.0			
The family should let Rebecca make the final decision about what she wants to do regarding the clinical trial $(5)^{b}$	5.4	1.4	0.4**	0.2**	0.5**	-0.1*	1.0		
The family should do whatever it takes to help Rebecca regardless of her wishes (6) ^b	4.3	1.7	0.2**	0.3**	0.03	0.5**	-0.1*	1.0	
Storyline Influence (7) ^c	4.5	1.4	0.4**	0.4**	0.2**	-0.4**	0.04	-0.4**	1.0

^aMeasured on a scale from 7 to 49, with a higher score indicating more identification

^bMeasured on a scale from 1 (strongly disagree) to 7 (strongly agree)

^cOn a scale from 1 (less influence) to 7 (strong influence)

* p < 0.05 ** p < 0.01

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. Focus group participants felt the storyline 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." (Female, 62 years old)

Finally, focus group participants felt that the disagreement between Kevin and Randall over Rebecca's care would encourage family discussion about care preferences. As one participant explained:

"I think it gives [viewers] an example ... they had tension because they weren't all together on how they should proceed." (Female, 48 years old)

Research Question 2

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); median personal experience of survey participants was 1 (IQR = 0–2]. 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).

Identification was the only predictor variable to be statistically significantly associated with all perception and behavioral intent outcome variables (Table 3). Attitudes toward medical research, personal experience, and male gender all had a positive, statistically significant association with Randall's insistence that Rebeca participate in the clinical trial, the perception that the family should do whatever it takes to help Rebecca regardless of her wishes, and storyline influence (Table 3).

All focus group participants reported some type of personal experience related to Alzheimer's disease or dementia and

caregiving. 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 progressed to the point where the loved one had to enter a care facility. Additionally, several participants described being the primary caregiver for a parent with Alzheimer's disease, which they noted was "24/7" 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, I would definitely promote a clinical trial." (Female, 65 years old)

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 one participant explained:

"I believe that it wouldn't necessarily save her [Rebecca] or even necessarily help her. But I do think that it would ... help those in the future." (Female, 48 years old)

Further in keeping with the survey results, focus group participants expressed strong support for clinical research more broadly. 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:

"I look at all these clinical trials really, really optimistically... ... 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... to maybe help somebody else in the future." (Male, 28 years old)

"I don't want to be away from family for nine months ... just to benefit science" while another said "I think it'd be a risk. Not sure I would send my mom." (Female, 52 years old)

Table 3. Associations between identification, attitudes toward medical research, personal experience, and socio-demographic character-	
istics with perceptions of the storyline and behavioral intention $(n = 720)$	

	Beta	SE	р
	Kevin's desire to re-	spect Rebecca's wishes to not participation	ate in the clinical trial
Identification	0.07	0.01	< 0.001
Medical Research	0.02	0.01	0.06
Experience	-0.03	0.03	0.32
Age	0.00	0.00	0.48
Gender	0.00	0.10	0.99
Race/Ethnicity	-0.05	0.08	0.52
Adjusted R ²	0.18		
-	Randall's in	sistence that Rebecca participate in th	e clinical trial
Identification	0.07	0.01	< 0.001
Medical Research	0.05	0.01	< 0.001
Experience	0.07	0.03	0.03
Age	0.00	0.00	0.81
Gender	0.53	0.08	< 0.001
Race/Ethnicity	0.03	0.08	0.66
Adjusted R ²	0.26		
	e family should let Rebecca mal	te the final decision about what she w	ants to do regarding the clinical trial
Identification	0.05	0.01	<0.001
Medical Research	0.02	0.01	0.09
Experience	-0.07	0.03	0.04
Age	0.01	0.00	0.09
Gender	-0.10	0.11	0.32
Race/Ethnicity	0.06	0.08	0.51
Adjusted R ²	0.10		
5	The family should d	o whatever it takes to help Rebecca re	gardless of her wishes
Identification	0.06	0.01	< 0.001
Medical Research	0.04	0.01	0.001
Experience	0.08	0.04	0.03
Age	0.00	0.00	0.59
Gender	0.65	0.12	< 0.001
Race/Ethnicity	0.10	0.09	0.30
Adjusted R ²	0.14		
		Seeing this storyline has influenced m	ne
Identification	0.17	0.04	< 0.001
Medical Research	0.54	0.05	<0.001
Experience	0.89	0.16	<0.001
Age	-0.04	0.02	0.01
Gender	1.78	0.51	<0.001
			0.20
Race/Ethnicity Adjusted R ²	-0.02 0.35	0.51 0.40	<0.001 0.95

Discussion

This study suggests the *This Is Us* storyline may be a promising way to positively promote these topics. Additionally, as the first study to examine the influence of a television entertainment narrative by triangulating survey and focus group results, the ways in which our qualitative findings allowed for further exploration of associations identified during the quantitative portion suggest this approach may be valuable for future research in this area.

While we hypothesized that viewers would identify with either Kevin or Randall and that identification with a character would be associated with stronger support for that character's plan for Rebecca, this hypothesis was not supported. Rather, triangulation of survey and focus group results suggests that while on screen Randall and Kevin's plans for addressing Rebecca's diagnosis are presented as at odds with each other, viewers perceptions are more nuanced. Specifically, participants related to Randall gathering information and insisting Rebecca seek medical care as well as Kevin's desire to keep Rebecca close to family. In other words— perhaps to simplify this complex issue for viewers—while on screen each character holds one point of view about Rebecca's care, focus group participants discussed holding both views within themselves as a single caregiver. This is consistent with previous qualitative research finding that caregivers of family members with dementia often experience complex thoughts and emotions as to the best care options for their loved one (Hovland & Mallett, 2021; Kontrimiene, Sauseriene, Blazeviciene, Raila, & Jaruseviciene, 2021). Future research could examine if our finding regarding the complexity of character identification is unique to this topic, or if it extends to other health topics. If the latter, future survey research examining the relationship between character identification and the influence of health storylines may benefit from a closer examination as to the components of a character's actions viewers most identify with.

Our conceptual framework included personal experience related to dementia and caregiving and attitudes toward medical research as components that may influence viewers' behavioral intent toward planning for aging, including potential participation in a clinical trial. Regarding personal experience, roughly half the sample of survey respondents and all focus group participants had a friend or close relative that had been previously diagnosed with dementia or Alzheimer's disease. While greater personal experience for survey respondents was 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). These results, as well as those from the focus groups, suggests that viewers with personal caregiving experience may identify with Randall's decision to override Rebecca's caregiving wishes due to their own experience making difficult caregiving decisions as dementia progresses. Consistent with prior research, these results suggest that prior personal experience is an important component to consider when assessing storyline influence (Quintero Johnson, Harrison, & Ouick, 2013).

In our sample, survey respondents indicated high levels of support for medical research, and this support was associated with Randall's insistence that Rebeca participate in the clinical trial, the perception that the family should do whatever it takes to help Rebecca regardless of her wishes, and storyline influence. These associations were expected given prior research suggesting more favorable attitudes toward medical research are associated with clinical trial participation (Anderson, Borfitz, & Getz, 2018). However, focus group responses suggest these associations may be nuanced, in that focus group participants were supportive of clinical trial participation, but not at the expense of relocating away from family. Prior research suggests the value in clinicians having conversations shortly after diagnosis with patients with Alzheimer's disease and their surrogate decision makers about participation in clinical research, but that such conversations are relatively rare (Howe, 2012). To facilitate such discussions, it may be valuable for clinicians to utilize clips from this storyline, particularly those that discuss Rebecca's relocation from family in order to participate in a clinical trial; such clips could promote family

discussions about participation in clinical research in a variety of situations (e.g. involving relocation versus not) and resolve disagreements in a supportive, moderated environment. It may also be valuable for health communication scholars to make clinicians aware of this storyline as a resource to recommend to patients and family members to watch upon diagnosis, and for future research to use mixed-methods to examine the impact of such a recommendation.

Of note, while our conceptual framework did not include the concept of stigma and our survey did not assess this concept, the potential for the storyline to reduce stigma related to treatment and caregiving emerged as a theme during the focus groups. Prior research has found that entertainment narratives with transgender characters may be an effective tool to decrease stigma toward transgender people (Gillig, Rosenthal, Murphy, & Folb, 2018b; Massey, Wong, & Barbati, 2021), and our results suggest this storyline could reduce stigma toward people demonstrating early symptoms of Alzheimer's disease. It would be valuable for future research to more directly assess the role of this storyline on decreasing stigma, perhaps in the context of Goffman's work around social interaction as theatrical performance (Goffman, 1959). These results also suggest the potential for clips from this storyline to be used as part of health promotion campaigns to encourage audiences to recognize and seek an evaluation for early symptoms.

Alternatively, an intervention featuring clips related to the disagreement between Kevin and Randall over Rebecca's care could be a valuable way to promote care planning discussions, which could reduce the significant stress family members often face regarding surrogate decision making (Fetherstonhaugh, McAuliffe, Bauer, & Shanley, 2017). Moreover, given that family conflict around surrogate decision making is associated with pursing more aggressive, expensive end-of life care for dementia patients, such an intervention could also potentially reduce healthcare costs (Harrison Dening, Sampson, & De Vries, 2019). Future research could implement and evaluate the impact of such campaigns.

Another avenue for future research could be examining the use of clips from this storyline as an intervention to address health disparities in Alzheimer's disease diagnosis and care. Alzheimer's disease is substantially underreported among Black or African-American populations in the U.S., likely due in part to misconceptions that dementia is a normal part of aging and stigma associated with Alzheimer's disease, as well as institutional racism in the medical system (Alzheimer's Association, 2020). In our linear regression models, race/ethnicity was not a statistically significant predictor variable; however, our sample was over 80% white. Considering the themes that emerged in the focus groups around Rebecca and her husband's denial about the severity of her symptoms and the ability of the storyline to reduce stigma, it would be valuable for future research to examine the potential influence of the storyline with more diverse samples and within the context of existing health disparities.

Although our results suggest the storyline may influence viewers' behavioral intent toward planning for aging, it should

be noted that we did not assess impact on actual health behavior, nor did we assess long-term influence of planning for one's own or a loved one's aging. Since we conducted this study, *This Is Us* has expanded the storyline, including depicting Rebecca's continued memory decline and eventual death, additional conflict between Kevin and Randall as to Rebecca's care, frustration experienced by Rebecca's husband and children over her inconsistent behaviors, and the impact of caregiving on these characters' well-being. Future research could build from our study to examine these aspects of the storyline as well as the long-term influence of this storyline or others on planning for aging.

Overall, themes identified during the focus groups related to personal experience, perceptions of medical research and clinical trials, and the influence of the storyline on behavioral intent suggest these relationships are complex and multifactorial. For example, focus group participants expressed support for Rebecca's participation in the clinical trial, while also expressing concern about participating in a trial that required moving away from loved ones. These findings support the value of mixed-methods studies when exploring the influence of entertainment narratives on health-related outcomes, and specifically the use of qualitative methods to explore the nuances of associations that emerge from quantitative findings.

Limitations

This study has several limitations that should be noted. First, we made the decision to use a cross-sectional survey because the storyline ran across most of the season, but this meant we could not compare pre and post-viewing responses. Second, although we employed several measures to increase the quality of survey responses, all survey information was obtained via self-report, and survey and focus group responses may be subject to social desirability bias. Third, our focus groups were relatively small in size, which may have limited the discussion. However, despite the small size, each focus group ran for approximately one hour as planned and researchers coding the transcripts observed thematic saturation, suggesting appropriate discussion. Fourth, due to the confidential nature of survey responses, we were unable to look specifically at responses for focus group participants and compare these responses to the broader sample. Finally, although responses to demographic items suggest survey respondents were similar to the general population of This Is Us viewers, participants were not randomly selected to participate in either the survey or focus groups.

Conclusion

Alzheimer's disease and caregiving affect an estimated 9 million U.S. adults. With the aging public it is critically important to raise awareness of the importance of advanced care planning related to aging. This study found that the *This Is Us* storyline, which reached approximately 12 million viewers at the time it aired, was a promising avenue through which to do so. Given that the average U.S. adult spends approximately 2,000 hours per year watching primetime television, it may be valuable for clinicians

and public health professionals to develop collaborative partnerships with the entertainment industry that leverage this vast exposure to promote health. This study also demonstrates the value of using mixed-methods, and our identification of potential focus group participants through survey participation offers a promising way for future researchers to use mixed-methods to explore other important topics related to health and media exposure. Future research can explore how to best tailor media messaging to be both educational and entertaining, and how healthcare professionals can best partner with television writers to generate such content.

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References

- Ajzen, I. (2002). Perceived behavioral control, self-efficacy, locus of control, and the theory of planned behavior1. *Journal of Applied Social Psychology*, 32(4), 665–683. doi:10.1111/J.1559-1816.2002.TB00236.X
- Anderson, A., Borfitz, D., & Getz, K. (2018). Global public attitudes about clinical research and patient experiences with clinical trials. JAMA Network Open, 1(6), e182969–e182969. doi:10.1001/ JAMANETWORKOPEN.2018.2969
- Anderson, C. N., Noar, S. M., & Rogers, B. D. (2013). The persuasive power of oral health promotion messages: a theory of planned behavior approach to dental checkups among young adults. *Health Commun*, 28 (3), 304–313. doi:10.1080/10410236.2012.684275
- Association, A. (2020). 2020 Alzheimer's disease facts and figures. *Alzheimer's and Dementia*, 16(3), 391–460. doi:10.1002/alz.12068
- Bae, H. S., & Kang, S. (2008). The influence of viewing an entertainment-education program on cornea donation intention: A test of the theory of planned behavior. *Health Commun*, 23(1), 87–95. doi:10.1080/10410230701808038
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, 41(5), 545–547. doi:10.1188/14.ONF.545-547
- Cheng, S. T. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Reports*, 19(9) Current Medicine Group LLC 1, 1–8. 10.1007/s11920-017-0818-2.
- Cohen, J. (2001). Defining identification: A theoretical look at the identification of audiences with media characters. *Mass Communication and Society*, 4(3), 245–264. doi:10.1207/S15327825MCS0403 01
- Fetherstonhaugh, D., McAuliffe, L., Bauer, M., & Shanley, C. (2017). Decision-making on behalf of people living with dementia: How do surrogate decision-makers decide? *Journal of Medical Ethics*, 43(1), 35–40. doi:10.1136/medethics-2015-103301
- Fisher, W. R. (2009). Narration as a human communication paradigm: The case of public moral argument. *Communication Monographs*, *51*(1), 1–22. doi:10.1080/03637758409390180
- Gerbner, G., Gross, L., Morgan, M., Signorielli, N., & Shanahan, J. (2002). Growing up with television: Cultivation processes. Erlbaum.
- Gillig, T. K., Rosenthal, E. L., Murphy, S. T., & Folb, K. L. (2018a). More than a media moment: the influence of televised storylines on viewers' attitudes toward transgender people and policies. *Sex Roles*, 78(7–8), 515–527. doi:10.1007/s11199-017-0816-1
- Gillig, T. K., Rosenthal, E. L., Murphy, S. T., & Folb, K. L. (2018b). More than a media moment: the influence of televised storylines on viewers' attitudes toward transgender people and policies. *Sex Roles*, 78(7–8), 515–527. doi:10.1007/s11199-017-0816-1
- Goffman, E. (1959). The presentation of self in everyday life. Anchor.
- Harrison Dening, K., Sampson, E. L., & De Vries, K. (2019). Advance care planning in dementia: Recommendations for healthcare professionals. In *Palliative care and social practice* (Vol. 12). Palliat Care. doi:10. 1177/1178224219826579.
- Hoffman, B. L., Shensa, A., Wessel, C. B., Hoffman, R., & Primack, B. A. (2017). Exposure to fictional medical television and health: A systematic review. *Health Educ Res*, 32(2), 107–123. doi:10.1093/ her/cyx034

Hollywood Health & Society. (2021). https://hollywoodhealthandsociety.org/

- Hovland, C. A., & Mallett, C. A. (2021). Family caregivers for older persons with dementia offer recommendations to current caregivers: A qualitative investigation. *Https*, 26(8) //Doi-Org.Pitt.Idm.Oclc.Org/ 10.1177/17449871211041682, 796–806. 10.1177/17449871211041682.
- Howe, E. (2012). Informed consent, participation in research, and the Alzheimer's patient. *Innovations in Clinical Neuroscience*, 9(5–6), /pmc/articles/PMC3398682/, 47.
- Kenner, A. M. (2008). Securing the elderly body: Dementia, surveillance, and the politics of "aging in place. Surveillance and Society, 5(3), 252–269. doi:10.24908/ss.v5i3.3423
- Kermel Schiffman, I., & Werner, P. (2021). Willingness of family caregivers of people with dementia to undertake advance care planning:

examining an extended model of the theory of planned behavior. *Dementia*, 20(3), 1044–1057. doi:10.1177/1471301220922761

- Kontrimiene, A., Sauseriene, J., Blazeviciene, A., Raila, G., & Jaruseviciene, L. (2021). Qualitative research of informal caregivers' personal experiences caring for older adults with dementia in Lithuania. *International Journal of Mental Health Systems*, 15(1), 1–10. doi:10. 1186/S13033-020-00428-W/TABLES/1
- Massey, Z. B., Wong, N. C. H., & Barbati, J. L. (2021). Meeting the (Trans)parent: test of parasocial contact with transgender characters on reducing stigma toward transgender people. *Communication Studies*, 72(2), 232–250. doi:10.1080/10510974.2021.1876125
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R., Kawas, C. H., Phelps, C. H. (2011). The diagnosis of dementia due to *Alzheimer*'s disease: Recommendations from the national institute on aging-*Alzheimer*'s association workgroups on diagnostic guidelines for *Alzheimer*'s disease. *Alzheimer's and Dementia*, 7 (3), 263–269. doi:10.1016/j.jalz.2011.03.005
- Montaño, D. E., & Kasprzyk, D. (2008). Chapter 4: Theory of reasoned action, theory of planned behavior, and the integrated behavioral model. In *Health behavior and health education: Theory, research, and practice* (4th ed., pp. 67–92). Jossey-Bass.
- Moyer-Gusé, E. (2008). Toward a theory of entertainment persuasion: Explaining the persuasive effects of entertainment-education messages. *Communication Theory*, *18*(3), 407–425. doi:10.1111/j. 1468-2885.2008.00328.x
- Murphy, S. T., Frank, L. B., Moran, M. B., & Patnoe-Woodley, P. (2011). Involved, transported, or emotional? Exploring the determinants of change in knowledge, attitudes, and behavior in entertainment-education. *Journal of Communication*, 61(3), 407–431. doi:10.1111/j.1460-2466.2011.01554.x
- Nielsen. (2017). For Us By Us? The mainstream appeal of black content Nielsen. https://www.nielsen.com/us/en/insights/article/2017/for-us-byus-the-mainstream-appeal-of-black-content/
- Nielsen Media Company. (2018). The Nielsen total audience report: Q1 2018. https://www.nielsen.com/us/en/insights/reports/2018/q1-2018total-audience-report.html
- Patton, M. Q. (1998). Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, 34(5), 1189–1208. http://www.ncbi. nlm.nih.gov/pmc/articles/PMC1089059/
- Preston, C., Drydakis, N., Forwood, S., Hughes, S., & Meads, C. (2019). What are the structural barriers to planning for later life? A scoping review of the literature. *Social Inclusion*, 7(3), 17–26. doi:10.17645/SI. V7I3.1883
- QSR International Pty Ltd. (2018). Nvivo 12 for windows (No. 12). QSR International. http://www.qsrinternational.com/nvivo-product
- Quintero Johnson, J. M., Harrison, K., & Quick, B. L. (2013). Understanding the effectiveness of the entertainment-education strategy: An investigation of how audience involvement, message processing, and message design influence health information recall. J Health Commun, 18(2), 160–178. doi:10.1080/10810730.2012.688244
- Rabarison, K. M., Bouldin, E. D., Bish, C. L., McGuire, L. C., Taylor, C. A., & Greenlund, K. J. (2018). The economic value of informal caregiving for persons with dementia: Results from 38 states, the district of Columbia, and Puerto Rico, 2015 and 2016 brfss. *American Journal of Public Health*, 108(10), 1370–1377. doi:10. 2105/AJPH.2018.304573
- Raymond, M., Warner, A., Davies, N., Iliffe, S., Manthorpe, J., & Ahmedzhai, S. (2014). Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia*, 13(1), 96–110. doi:10.1177/ 1471301212450538
- Rubright, J. D., Cary, M. S., Karlawish, J. H., & Kim, S. Y. H. (2011). Measuring how people view biomedical research: Reliability and validity analysis of the research attitudes questionnaire. *Journal of Empirical Research on Human Research Ethics*, 6(1), 63–68. doi:10.1525/jer. 2011.6.1.63

- Santiago, A. L. H. (2017). The 10 highest-rated TV shows of 2017, according to Nielsen ratings. Business Insider. https://www.businessinsider.com/the-10-highest-rated-tv-shows-of-2017-according-to-nielsenratings-2017-12
- StataCorp. (2020). *Stata statistical software: Version 16* (16th ed.). StataCorp.
- Sussman, T., Pimienta, R., & Hayward, A. (2021). Engaging persons with dementia in advance care planning: Challenges and opportunities. *Dementia*, 20(6), 1859–1874. doi:10.1177/1471301220973059
- Wolfs, C. A. G., de Vugt, M. E., Verkaaik, M., Haufe, M., Verkade, P. J., Verhey, F. R. J., & Stevens, F. (2012). Rational decision-making about treatment and care in dementia: A contradiction in terms? *Patient Education and Counseling*, 87(1), 43–48. doi:10.1016/j.pec.2011.07.023
- Yoo, J. H., & Tian, Y. (2011). Effects of entertainment (mis) education: Exposure to entertainment television programs and organ donation intention. *Health Communication*, 26(2), 147–158. doi:10.1080/ 10410236.2010.542572
- Zoom. (n.d.). Zoom video communications, Inc. Retrieved January 3, 2021, from https://zoom.us/

Appendix A. Personal experience and behavioral intent items

Personal experience items (n = 720)

	Freq	uency
Statement	Ν	%
Has a friend or close relative that has been previously diagnosed with dementia or Alzheimer's disease	312	43.3
Took care of a friend or close relative with dementia or Alzheimer's disease in the past	143	19.9
Is currently taking care of a friend or close relative with dementia or Alzheimer's disease	67	9.3
Is currently taking care of a friend or close relative due to normal aging	67	9.3
Is currently taking care of a friend or close relative with a chronic condition	60	8.3
Has seen another member of the family (e.g. mom, dad) take care of a friend or close relative with dementia or Alzheimer's disease	200	27.8
Expects in the future to take care of a friend or close relative with dementia or Alzheimer's disease	117	16.3
Has received formal training in caring for people with dementia or Alzheimer's disease (e.g. medical school, EMT certification, nursing courses)	55	7.4
Has studied gerontology (the scientific study of aging) in school	29	4.0
Has worked in the past caring for people with dementia or Alzheimer's	63	8.8
Currently works caring for people with dementia or Alzheimer's disease	21	2.9

Mean Score and Standard Deviation for Items Assessing Storyline's Influence on 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)

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