False Memories for End-of-Life Decisions

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Objective: To examine people’s false memories for end-of-life decisions. Design: In Study 1, older adults decided which life-sustaining treatments they want if they were seriously ill. They made these judgments twice, approximately 12 months apart. At Time 2, older adults and their self-selected surrogate decision makers tried to recall the older adults’ Time 1 decisions. In Study 2, younger adults made treatment decisions twice, approximately 4 months apart. At Time 2, younger adults tried to recall their Time 1 decisions. Main Outcome Measures: Percentage of participants who falsely remembered that their original treatment decisions were the same as their current decisions. Results: In Study 1, older adults falsely remembered that 75% of their original decisions were the same as their current decisions; surrogates falsely thought that 86% of older adults’ decisions were the same. In Study 2, younger adults falsely remembered that 69% of their original decisions were the same as their current decisions. Conclusion: Age alone cannot account for people’s false memories of their end-of-life decisions; we discuss other mechanisms. The results have practical implications for policies that encourage people to make legal documents specifying their end-of-life treatment decisions.

Keywords: brief phrases, advance directives, memory, false memories, older adults, surrogates

Intense publicity surrounding the removal from life-support of a severely brain-damaged Florida woman named Terri Schiavo increased public awareness of advance directives (ADs). People use ADs to document the treatments they want to receive if they become too ill to communicate (such instructional ADs are often called “living wills”), or to authorize surrogates to make medical decisions on their behalf. ADs are widely advocated as a crucial way to avoid the conflict of Schiavo’s final days, and public interest in completing ADs increased dramatically after her death (Pew Research Center, 2006; Schwartz & Estrin, 2005).

However, research (Ditto, 2006; Ditto, Hawkins, & Pizarro, 2006; Dresser, 2003) has raised questions about the effectiveness of ADs in end-of-life decision making. Consequently, the President’s Council on Bioethics (2005) cautioned against uncritical reliance on ADs for several reasons, including people’s inability to fully comprehend serious and complex medical situations.

One important problem is whether medical decisions made well in advance of illness still reflect current preferences. Numerous studies (Ditto et al., 2003; Fried et al., 2006) have shown that many people change their life-sustaining treatment preferences within a few months to 2 years. Although we might suppose that changing preferences would lead people to update their old ADs accordingly, the danger is that some people will not realize that their preferences have changed—and thus see no reason to update their ADs or inform their surrogate decision makers. In a worst-case scenario, outdated ADs could lead individuals who want life-sustaining treatment to not be given it, or individuals who do not want life-sustaining treatment to have their life prolonged against their wishes.

Indeed, the nonmedical literature shows that people often do not realize that their preferences and attitudes have changed (Markus, 1986; Ross, 1989). Only one small study in the medical literature has examined if people realized when their treatment preferences have changed. Gready et al. (2000) asked a small, convenience sample of people 65 years old and older to consider several common end-of-life illness scenarios (e.g., Alzheimer’s disease) and choose the treatments they would want to receive if necessary (e.g., antibiotics if they contracted pneumonia). Two years later, they made the same decisions again. Not only did the participants change about 25% of their decisions (such as from not wanting treatment to wanting it), but 80% of the time they did not realize it. In other words, these older adults falsely remembered that their original decisions were the same as their current decisions.

In Study 1, we used a large sample of older adults and their surrogate decision makers to examine false memories about past treatment decisions. We examined the prevalence of these memories and whether they are influenced by age and gender. More important, we also examined the memories of surrogates—people who might be asked to make treatment decisions if the older adults were unable to communicate. In Study 2, we investigated whether younger adults were also susceptible to false treatment memories.
We reasoned that if these memories were caused by age-related memory impairments, they should occur rarely in younger adults.

Study 1

Method

Participants

Participants were 332 adults (43% male; 67 to 96 years of age at Time 2^1(T2), \( M = 74.7, SD = 5.1 \)) who participated as part of the Advance Directives, Values Assessment, and Communication Enhancement (ADVANCE) project (see Ditto et al., 2001; Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006; Ditto et al., 2003). Surrogates were 329 adults (33% male, 29 to 88 years of age, \( M = 62.2, SD = 13.2 \)). Participants chose their own surrogates, people whom they would want to make medical decisions for them if they could not communicate.

Materials and Procedure

Participants were interviewed twice, approximately 12 months apart (\( M = 379 \) days, \( SD = 46 \) days).

Time 1 (T1). We told the participants that we were investigating end-of-life medical decisions without mentioning the focus on memory. Participants completed Ditto et al.’s (2001) Life Support Preferences/Predictions Questionnaire (LSPQ), briefly imagining themselves in nine common end-of-life scenarios (see Table 1). For example, participants imagining Alzheimer’s disease were told:

You have trouble remembering things and thinking clearly. You cannot always recognize people you know. You have no chance of recovery. Your mental abilities may get worse quickly or you may stay the way you are now for a long time. Your physical condition and abilities are unaffected.

Then participants indicated whether they would want to receive each of four medical treatments (see Table 1). For example, they were asked, “If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?” Participants made their treatment decisions using a scale ranging from 1 (definitely would not want), 2 (probably would not want), 3 (unsure), 4 (probably would want), to 5 (definitely would want). In total, participants made 35 decisions (9 Health Scenarios \( \times \) 4 Treatments, except they did not consider tube feeding in their current health state). Four of these decisions were our critical items (cardiopulmonary resuscitation [CPR] and tube feeding decisions in Scenarios 5b and 6a); they were chosen a priori because they do not encourage modal responses (e.g., all participants wanting or not wanting treatment).

Surrogates were interviewed separately in one of five conditions (see Ditto et al., 2001). Most surrogates reviewed their target’s written ADs, which either described treatment decisions given in response to six hypothetical scenarios (Emanuel, 1991) or described the activities that targets said were so important that they would not want to live if they could not do them (Ditto, Druley, Moore, Danks, & Smucker, 1996). Half of the surrogates also discussed targets’ written ADs with them. Other surrogates did not review nor discuss targets’ written ADs. All surrogates used the LPSQ to predict the treatments that their targets would want to receive.

T2. Participants and surrogates returned for a follow-up interview, which followed the same procedure as T1, except that participants also indicated whether each of their decisions for the four critical items was the same as those from the first interview based on a scale ranging from 1 (very sure it was the same), 2 (pretty sure it was the same), 3 (unsure), 4 (pretty sure it has changed), to 5 (very sure it has changed). We dichotomized these memory judgments into same (ratings of 1 to 2) or changed (ratings of 3 to 5). We asked surrogates to use the same scale to report whether they thought that their targets had changed their minds about any treatment decisions.

Results and Discussion

Participants

Overall, 332 participants made 1,328 critical decisions. In line with previous research (Ditto et al., 2001; 2003; Gready et al., 2000; Uhlmann, Pearlman, & Cain, 1988), we dichotomized each decision into not want (responses of 1 to 2) and want (responses of 3 to 5). We defined a changed preference as one that switched from one side of the dichotomy to the other (e.g., from wanting to not wanting treatment or vice versa)^2. As Table 2 shows, participants changed 312 of their 1,328 critical decisions (23%). Changes were more likely to be from wanting treatment to not wanting treatment (62% of changes) than the reverse (38% of changes), \( z = 6.09, p < .01 \). Most important, however, of the participants who changed their decisions, 75% falsely remembered that their T2 decisions were the same as their original decisions—a figure similar to the

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1 We use the labels Time 1 and Time 2 although these data were collected at Time 2 and Time 3 in the ADVANCE project.
2 We included “unsure” responses in the “want” category to be consistent with past research (e.g., Ditto et al., 2003; Uhlmann et al., 1988) and standard medical practice: when patients are unsure about receiving treatment and cannot communicate the common presumption is to treat them. Our dichotomization underestimates any potential effects.
80% reported by Gready et al. (2000). Indeed, for each of the four treatments, participants experienced false memories for at least 70% of their decisions.

We used logistic regression to investigate whether participants’ age and gender predicted their false memories in each critical scenario. Age was not a significant predictor, but gender was: men were over four times more likely to falsely remember their tube feeding decisions when they considered having cancer, \( B = 4.2, p < .01, \text{OR} = 2.8 \).

The right side of Table 2 shows another type of false memory—participants’ false memories of change. Here, only 11% of participants falsely remembered that their new decisions were different from their original decisions. False “change” memories were less prevalent than false “same” memories, \( z = 22.69, p < .01 \).

To investigate participants’ confidence about both types of false memory, we compared participants’ continuous memory ratings for those who had false memories with those who had correct memories. The left side of Table 3 shows participants who remembered—either falsely or correctly—that their decisions had stayed the same. Overall, for all four scenarios, both participants with false memories and those with correct memories rated that they were very sure to pretty sure that their decisions were the same; that is, their mean ratings were between 1 and 2 on the scale. For the two stroke scenarios, participants with false memories were slightly less confident that their decisions had stayed the same than those with correct memories. For the two cancer scenarios, participants with false memories were no less confident that their decisions had stayed the same than those with correct memories.

The right side of Table 3 shows participants who remembered that their decisions had changed. Overall, for all four scenarios, both participants with false memories and those with correct memories rated that they were unsure to pretty sure that their decisions had changed; that is, their mean ratings were between 3 and 4 on the scale. For all four scenarios, participants with false memories were no less confident that their decisions had stayed the same than those with correct memories. Taken together, these confidence ratings suggest that participants with false memories were as confident about their memories as those with correct memories.

### Table 2

<table>
<thead>
<tr>
<th>Decision changed</th>
<th>Correctly remembered change %</th>
<th>Decision stayed the same</th>
<th>Correctly remembered same %</th>
<th>Falsely remembered change %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall n</td>
<td></td>
<td>Overall n</td>
<td>Correctly remembered same %</td>
</tr>
<tr>
<td>Study 1: Older adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke CPR</td>
<td>88</td>
<td>78.4</td>
<td>21.6</td>
<td>244</td>
</tr>
<tr>
<td>Stroke tube</td>
<td>83</td>
<td>77.1</td>
<td>22.9</td>
<td>249</td>
</tr>
<tr>
<td>Cancer CPR</td>
<td>77</td>
<td>72.7</td>
<td>27.3</td>
<td>255</td>
</tr>
<tr>
<td>Cancer tube</td>
<td>64</td>
<td>70.3</td>
<td>29.7</td>
<td>268</td>
</tr>
<tr>
<td>Overall</td>
<td>312</td>
<td>75.0</td>
<td>25.0</td>
<td>1,016</td>
</tr>
<tr>
<td>Study 2: Younger adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Stroke CPR</td>
<td>5</td>
<td>60.0</td>
<td>40.0</td>
<td>26</td>
</tr>
<tr>
<td>Stroke tube</td>
<td>7</td>
<td>85.7</td>
<td>14.3</td>
<td>24</td>
</tr>
<tr>
<td>Cancer CPR</td>
<td>8</td>
<td>62.5</td>
<td>37.5</td>
<td>23</td>
</tr>
<tr>
<td>Cancer tube</td>
<td>9</td>
<td>66.7</td>
<td>33.3</td>
<td>22</td>
</tr>
<tr>
<td>Overall</td>
<td>29</td>
<td>69.0</td>
<td>31.0</td>
<td>95</td>
</tr>
</tbody>
</table>

**Note.** CPR = cardiopulmonary resuscitation; tube = tube feeding; \( n \) = number of decisions.

Surrogates correctly predicted approximately two thirds of targets’ T1 treatment decisions (stroke/CPR = 69%, stroke/tube feeding = 66%, cancer/CPR = 67%, cancer/tube feeding = 70%). Whether surrogates reviewed or discussed targets’ ADs did not affect the accuracy of their predictions, \( ps > .31 \) (see also Ditto et al., 2001).

To examine whether surrogates realized when their targets changed their decisions, we focused on the surrogates who correctly predicted their target’s decisions at T1. That is, the following analyses only include surrogates who knew their target’s T1 decision. The left column of Table 4 shows the total number of surrogates who made correct T1 predictions for each scenario when their target’s decision changed from T1 to T2. Across all scenarios, 86% of the time surrogates incorrectly thought that their target’s decisions had stayed the same. This figure is higher than participants’ false “same” memories, \( z = 2.70, p < .01 \); which indicates that surrogates were worse than participants at recognizing when treatment decisions change. The right side of Table 4 shows that when their target’s decisions stayed the same, surrogates incorrectly thought that their target’s decisions had changed 8% of the time. This figure is different from participants’ false “change” memories, \( z = 1.73, ns \).

To investigate surrogates’ confidence about their false memories, we compared memory ratings for surrogates who had false memories with those who had correct memories. Table 3 shows...
that, for three of the four scenarios, surrogates who falsely remem-
bered that their target’s decisions had stayed the same were no less
confident than those with correct memories. Only surrogates who
falsely remembered that their target’s stroke CPR decision had
stayed the same were slightly less confident than those with correct
memories.

In addition, for three of the four scenarios, surrogates who
falsely remembered that their target’s decisions had changed were
no less confident than surrogates with correct memories. Only surrogates who
falsely remembered that their target’s cancer CPR decision had changed were slightly less confident than surrogates with correct memories. Overall, these confidence results suggest that surrogates with false memories about their targets’ decisions were as confident about their memories as surrogates with correct memories.

Study 2

Study 1 produced three major findings. First, after 12 months, older
adults changed their minds about almost a quarter of their treatment
decisions. Second, when they changed their minds, they falsely re-
membered 75% of their original treatment decisions, believing that
those decisions were the same as their current decisions. Third,
surrogates incorrectly thought that 86% of their target’s original
treatment decisions were the same as their current decisions.

In Study 2, we investigated whether younger adults also have
these false memories. Although younger adults experience life-
threatening situations less often than older adults, their decisions
are equally important. Indeed, the most famous cases of end-of-life
medical decision making (and the most important for generating
case law) all involved people who lost their decisional capacity
while in their 20s—Karen Ann Quinlan, Nancy Cruzan, and Terri
Schiavo. Given their relatively better memories, we might expect
that younger adults would rarely show the same kinds of false
memories that we found in Study 1. However, if we found that
younger adults often falsely remember their advance treatment
decisions—especially under circumstances that should promote
accurate memory—it would suggest that processes other than
age-related declines contribute to these false memories.

Method

Participants

Participants were 31 undergraduate psychology students (42%
male; 17 to 21 years of age, $M = 18.48, SD = 1.03$) from the
University of New South Wales. They participated in return for course credit.

Materials and Procedure

Participants took part in two sessions. We told them that we were investigating people’s advance medical decisions without mentioning the focus on memory. Participants completed the LSPQ. Approximately 4 months later ($M = 126$ days, $SD = 7$ days), participants returned for T2, which they thought would examine the test–retest reliability of the LSPQ. We chose 4 months because it is consistent with the briefest intervals used to assess stability of older adults’ treatment decisions, and should minimize memory errors (e.g., Berger & Majerovitz, 1998). The procedure was the same as in T1, except that after participants completed the LSPQ, we asked them “do you think that the answers you gave today are the same as the answers you gave in the first session?”

Results and Discussion

Overall, 31 participants made 124 critical decisions about the same four treatments as in Study 1. The left side of Table 2 shows the number of participants who changed their decisions from T1 to T2. Overall, participants changed 29 of their 124 decisions (23%). Unlike the older adults in Study 1, they were no more likely to change from wanting treatment to not wanting treatment (59% of changes) than the reverse (41% of changes), $z = 1.31, ns$. Most important, participants who changed their preferences falsely remembered that 69% of their current decisions were the same as their original decisions. Indeed, these false memories were as high as 86% for participants’ tube feeding decisions in the stroke scenario. Logistic regressions revealed that neither participants’ age nor gender predicted their false memories. The right side of Table 2 shows participants’ false memories of change. As in Study 1, participants were less likely to have false memories of change than false memories of stability, $z = 3.06, p < .01$.

General Discussion

Across two studies, we found false memories for life-sustaining treatment decisions in both participants and surrogates. For the majority of decisions that did not change, both participants and surrogates correctly reported that participants’ past decisions were the same as their current ones. However, when those decisions did change, most participants and surrogates falsely recalled that participants’ past decisions were the same as their current ones. Moreover, participants and surrogates with false memories of treatment decisions were just as confident about their memories as those with correct memories. These findings replicate Greedy et al.’s (2000) results with a much larger sample and extend them to surrogate decision makers.

False treatment memories were prevalent in younger as well as older adults, which indicate that age-related memory impairments cannot entirely account for these findings. Older adults may have been affected by age-related impairments, such as those found in working memory, episodic memory, prospective memory, and recollection (Hoyer & Verhaeghen, 2006); however, these impairments cannot entirely explain their false memories because younger adults also experienced them. In fact, the similar performance between older and younger adults is especially striking, considering that the 1-year retention interval should have disadvantaged the older adults relative to the younger adults.

The poor memory shown by younger adults, even over the shorter retention interval, may be due in part to the lower importance the younger adults likely placed on end-of-life decision making. More interesting, in Study 1, we found that male older adults had more false memories than females, and men have also been found to place less importance than women on dying with dignity (Bookwala et al., 2001). The similar rate of memory errors in the two studies is also consistent with research showing that older and younger adults’ focus can eliminate age differences in memory for health-related material. Løckenhoff and Carstensen (2007) found no difference in older and younger adults’ recall when both groups focused on the specific facts about their health-related decisions; however, younger adults recalled more decisions than older adults when both groups focused on their feelings. Thus, age might not have played a role in our studies because older and younger adults were equally focused on recalling facts about their original decisions (that is, the decisions themselves) rather than focusing on how they were feeling.

Why might young and old alike have such difficulty remembering their changed end-of-life decisions? First, research has repeatedly shown that people can come to remember all manner of events that never happened (e.g., Loftus, Miller, & Burns, 1978; Wade, Garry, Read, & Lindsay, 2002). Misremembering medical decisions is just another example of how wide-ranging memory distortions can be. Second, considerable research also has suggested that people often construct preferences “online” rather than retrieving them from memory (Bem, 1972; Nisbett & Wilson, 1977; Slovic, 1995). When asked to recall their earlier decisions, participants may have relied on implicit assumptions that their preferences had not changed and simply assumed that their past wishes were the same as their current ones (Ditto, Hawkins, & Pizarro, 2006; Ross, 1989). The mechanisms underlying false memories for end-of-life decisions is worthy of future research.

Our results suggest that memory distortions can be added to a growing list of problems associated with ADs (President’s Council on Bioethics, 2005). Most ADs recommend that people make new ADs if their old ones no longer reflect their wishes (e.g., American Bar Association Commission on Law and Aging, 2005). However, our research suggests that following such advice may be difficult because people are often unaware that their treatment wishes have changed. Instead, we recommend that policy encourage people to review and update their ADs after prescribed periods of time or major health changes. For example, the Patient Self-Determination Act (1990) requires that patients’ AD status be checked on hospital admission. Perhaps it should also require that the date of any ADs be checked and any “expired” ADs updated. Although determining the appropriate expiration period would require extensive empirical work, this mandatory updating addresses both the potential instability of people’s life-sustaining treatment decisions and that these decisions often change without people’s awareness. Above all, we must be sure that ADs speak for people—and speak accurately—when people cannot speak for themselves.

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4 We thank an anonymous reviewer for observing this point.
References


