



Case Study: 'What would they want?': Honouring decisions in dementia



the british
psychological society
the psychologist

This article has been sourced from the BPS, written by Emma Young on 05 June 2024 and can be accessed directly via the link below:

<https://www.bps.org.uk/research-digest/what-would-they-want-honouring-decisions-dementia>

Article

The article explores a complex ethical dilemma: should a person's earlier medical treatment preferences, made before developing dementia, be honored over their later preferences expressed after significant cognitive decline?

Imagine that, at the age of 50, your friend tells you that if they go on to develop dementia and then another physical illness that could be fatal if untreated, they wouldn't want that treatment. Then imagine that it's 30 years in the future, and they are in that exact, awful situation. Due to the dementia — which, in this theoretical scenario, is still incurable — they've suffered a substantial loss of cognitive function. Only now, they're saying that they *do* want treatment for the physical disease. Which treatment preference would you feel compelled to honour? James Toomey at Pace University and colleagues recruited 1445 US-based adults, who were gender matched to explore this difficult question.

The participants read a series of vignettes in which the initial and later decisions about treatment varied — so that in some, the pre-dementia decision was 'no-treatment' but the post-dementia decision was 'treatment', while in others it was the other way around. Scenarios varied in whether the subject was the participant themselves, a best friend, or a stranger. Across these conditions, participants generally believed that the *later* preference should be respected — except when they were the person in question, in which case they leaned toward honoring the *earlier* decision. Results from some other measures used in the study provide some insight into the reasons for this discrepancy. All participants indicated on a six-point scale the extent to which they believed the person in the vignette was still their 'true self'. This measure tapped into their judgements about the extent to which this person with substantial cognitive decline was still the same person, deep down. The team found clear links between scores on this scale and the participants' decisions. They felt that someone else — whether their best friend or a stranger — with the degree of cognitive decline described would still be closer to their true self than they would be. As the team writes, if the participant thought the person in the vignette was still their true self, despite their dementia, they were more likely to defer to their later treatment preference.

This finding challenges traditional bioethical and medical standards, which typically prioritise decisions made while a person is cognitively intact. The study suggests that the general public places more weight on the persistence of personal identity over cognitive ability when making moral decisions about medical treatment. Crucially, this could impact surrogate decision-making, as people might underestimate how their loved ones would want earlier preferences to be respected. This raises questions about how to ethically and accurately make decisions for those unable to speak for themselves.

The study has limitations — including its non-representative U.S. sample — but it underscores the need for further research. It also brings attention to a deeper societal and ethical issue: how we define personhood and autonomy in the context of dementia, and how that affects crucial medical decisions.

To access the full paper, please visit the article and follow the link at the very bottom: <https://doi.org/10.1080/23294515.2024.2336900>

The British Psychological Society (BPS) publishes articles like this regularly, with free access, under the Research Digest section of its website.

<https://www.bps.org.uk/collections/research-digest>

To access this article, the full research paper or others like it, please follow the link above.





Case Study: 'What would they want?': Honouring decisions in dementia

Links to Specification

2.1.6 Developmental psychology in memory, including at:

- The impact of Alzheimer's on older people and the effects on their memory.

2.4 Key questions

2.6 Issues and debates

- Practical issues in the design and implementation of research
- Issues of social control
- The use of psychological knowledge within society
- Issues related to socially sensitive research

9.3 Issues and debates

- Practical issues in the design and implementation of research
- Issues of social control
- The use of psychological knowledge within society
- Issues related to socially sensitive research

Recommended revision and research activities:

1. In the UK individuals can make an Advance Decision to Refuse Treatment (ADRT). An ADRT, sometimes referred to as a "living will," allows individuals to refuse specific medical treatments in advance. This becomes applicable if they lose the capacity to make or communicate decisions. In light of the article's findings what should be considered regarding an ADRT?
2. Research real-world ethical arguments about surrogate medical decision-making. Then, stage or write a debate addressing the question: "Who should have the final say when a person with dementia gives a new treatment preference—doctors, family, or the person themselves?"

Challenge task: Interview 3–5 people of different ages (e.g. a teenager, a parent, a grandparent) about their views on whether earlier or later medical treatment preferences should be respected if someone develops dementia. Compare their answers and analyse whether views vary by age or personal experience with dementia.

Exam style questions*

1. Explain one conclusion from this study. (2)
2. Explain one weakness of the sample used in this study. (2)
3. Explain one strength of the sample used in this study. (2)

[\(Click here to view Model Response sections\)](#)

Additional questions for which the content of the article can be used as part of a response

1. Assess socially sensitive research in Cognitive Psychology. (8)
2. Discuss your Key Question in Cognitive Psychology. (8)

*Exam style questions are not necessarily the exact format of those that will appear in the qualification examination papers but are written to elicit student responses that meet the assessment criteria, which are exemplified by the answers provided. The length of response in the answers is not indicative of expected student responses, and are provided to support centre teaching, student practice and self-assessment.





Case Study: 'What would they want?': Honouring decisions in dementia

Model Response - [Click here to return to question page](#)

Exam style questions:

1. Explain one conclusion from this study. (2)

- The general public places more weight on the persistence of personal identity over cognitive ability when making moral decisions about medical treatment. For example, participants were more likely to conclude that others with substantial cognitive decline were still their “true selves,” which correlated with increased preference to their post dementia preference.

2. Explain one weakness of the sample used in this study. (2)

- One weakness is that the study is not representative. For example, the researchers state that the sample is a non-representative in the US because it is possible a more diverse sample in the US may answer the questions differently. Consequently, the results on treatment decisions post dementia diagnosis cannot be generalised to the US population and more broadly other countries.

3. Explain one strength of the sample used in this study. (2)

- One strength of the sample used is that they were able to collect a large data set. For example, 1445 US-based adults completed the questionnaire. The sample size will control for anomalies in the data because the 1445 ppts will produce a large amount of data. This will make the results on which treatment preference would you feel compelled to honour (pre or post diagnosis) more accurate as anomalies will not skew results. Making the research valid on which treatment wishes should be honored for individuals with dementia.

Marks awarded and commentary

1. This response would achieve full marks: identifying a conclusion (personal identity over diagnosis) (1) and justifying with a result from the questionnaire regarding the correlation (1).
2. This response would achieve full marks: identifying the weakness of representativeness (1) and justifying ethnocentrism affecting the generalisability (1).
3. This response would achieve full marks: identifying ;large data set(1) and justifying controlling for anomalies resulting in accurate results making the findings valid. (1).

**** Note the difference between response 2 and 3. When writing about representativeness the justification is explaining the diversity of the sample however, when looking at sample size students should be evaluating how this affects the data as it is incorrect to say that it affects representativeness.**





Case Study: 'What would they want?': Honouring decisions in dementia

Model Responses - ([Click here to return to question page](#))

Additional questions for which the content of the article can be used as part of a response

1. Assess socially sensitive research in Cognitive Psychology. (8)

The following paragraphs could form part of the answer to this question:

(AO1) Toomey explored whether people believe medical treatment preferences made before dementia should outweigh those made after significant cognitive decline. 1,445 U.S. adults were presented with vignettes involving a person (themselves, a friend, or a stranger) who had made a treatment decision before developing dementia, then expressed a different preference later. Participants chose which preference to honour. Results showed that most participants favoured the later, post-dementia preference, especially when the person in the scenario was someone else. However, when considering themselves, participants were more likely to respect their earlier wishes. Judgments were influenced by whether they believed the person with dementia was still their "true self." The study concluded that people value the continuity of self over cognitive ability when making surrogate decisions. These findings challenge legal and medical norms, suggesting a gap between professional ethics and public moral intuitions.

(AO3) The results are socially sensitive because they affect those living with dementia. Having dementia makes them vulnerable due to their cognitive decline. In particular, the study suggested that their later decisions might be more valid than earlier ones, could raise ethical concerns because they could lack understanding of the consequences despite, they feel a truer sense of self. This could have a negative impact on the remainder of their quality of life. Making the research socially sensitive. The implication is that ethical safeguards need to be examined further when looking into the autonomy of patients with dementia making decisions regarding their medical treatment apart from their dementia.

2. Discuss your Key Question in Cognitive Psychology. (8)

How can psychologists' understanding of memory help patients with dementia?

The following paragraphs could form part of the answer to this question:

(AO2) Psychologists' understanding of memory can help improve the care and treatment of patients with dementia by informing how we interpret their decisions and behaviour. For example, Psychologists can help caregivers communicate more effectively and make ethically sound decisions. In dementia, especially Alzheimer's disease, episodic memory is often one of the first and most severely affected areas. Patients may forget recent conversations, what they had for breakfast, or important life events. Suggesting that making decisions regarding health conditions can be difficult for individuals with dementia to make as well as the caregivers supporting them. However, the study by Toomey et al. (2023) shows that people often believe those with dementia remain their "true selves" despite memory loss and are more likely to respect treatment decisions made *after* cognitive decline. This highlights the importance of understanding retrospective and prospective memory, as well as the continuity of self—an idea closely linked to long-term memory and personal identity. (AO1) This will benefit the individual with dementia, as by understanding memory distortion and decline it may help design better advance care plans or support caregiver decision-making, ensuring that patients' past and present wishes are balanced with respect and care. This key question is relevant to society because as of 2024, approximately 982,000 people are living with dementia in the UK, with projections indicating this number will rise to 1.4 million by 2040.

Level awarded and commentary

1. Assess socially sensitive research in Cognitive Psychology. (8)

The first paragraph (AO1) demonstrates accurate and thorough knowledge and understanding of a piece of research in Cognitive Psychology. It explains the aims, the sample and the results. Paragraph two (AO3) identifies how the research findings are socially sensitive by explaining how the people affected are vulnerable. Judgement is made and an implication of the research being socially sensitive is included with the inclusion of a competing arguments. Similarly structured paragraphs including other pieces of research from Cognitive Psychology would form a level 4 response overall.

2. Discuss your Key Question in Cognitive Psychology. (8)

The first paragraph (AO2) demonstrates application of Cognitive Psychology to explain dementia (procedural memory) and the continuation of the Toomey research. All applied and not generic. The last part of paragraph one is AO1, which explain the impact on the individual and the relevance of the key question. Further structured paragraphs would achieve a level 4 response.

