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Attitudes of Lay People to Withdrawal of Treatment in Brain Damaged Patients

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Abstract

Background Whether patients in the vegetative state (VS), minimally conscious state (MCS) or the clinically related locked-in syndrome (LIS) should be kept alive is a matter of intense controversy. This study aimed to examine the moral attitudes of lay people to these questions, and the values and other factors that underlie these attitudes.

Method One hundred ninety-nine US residents completed a survey using the online platform Mechanical Turk, comprising demographic questions, agreement with treatment withdrawal from each of the conditions, agreement with a series of ethical principles and three personality tests.

Results More supported treatment withdrawal from VS (40.2 % agreed, 17.6 % disagreed) than MCS (20.6 %, 41.2 %) or LIS (25.3 %, 35.8 %). Agreement with treatment withdrawal was negatively correlated

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Conclusion Lay attitudes to withdrawal of treatment in brain damaged patients are largely shaped by values similar to those central to the secular ethical debate. Neither traditional values such as the sanctity of life nor utilitarian values relating to resource allocation seem to play a central role. Far greater weight is given to autonomy, which may explain why participants were far more willing to endorse withdrawal of treatment when the issue was presented in the first person, or in relation to a concrete case involving a patient's explicit wishes. Surveys focusing on abstract cases presented in the third person may not provide an accurate picture of lay attitudes to these critical ethical questions.

Keywords Moral psychology · Withdrawal of treatment · Disorders of consciousness · Vegetative state · Minimally conscious state · Locked in syndrome

Introduction

Because of advances in modern medicine, patients are increasingly surviving significant cognitive injury to remain in states of diminished consciousness [1, 2]. Patients in these states—the vegetative state (VS) and minimally conscious state (MCS) as well as in the clinically related condition of locked-in syndrome (LIS), where consciousness is unaffected—may be kept alive almost indefinitely via the provision of artificial nutrition and hydration. Whether patients in these conditions *should* be kept alive in this way is, however, a matter of intense controversy. This study applies the novel field of empirical ethics to provide a new perspective on this discourse.

This issue has received extensive attention from clinicians, legal experts, and ethicists; however, less is known about the views of lay people. This is especially true of lay views about the MCS and LIS, which are less familiar to the general public than the VS. Although lay attitudes cannot decide these moral issues, the degree to which the general public finds withdrawal of treatment acceptable can affect the prospects of policy in this direction.

The aim of the present study was to shed light on attitudes to withdrawal of treatment from patients with these forms of brain damage. Unlike most previous studies, we focused here on the attitudes of lay people, not of medical doctors or clinicians and explored the values and psychological dispositions that may underlie these views.

Background

Disorders of Consciousness

VS describes patients with normal sleep-wake cycles though no evidence of awareness of self or environment. Studies performed so far suggest that these patients cannot feel pain [3–5]. No motor, sensory or visual function is observed beyond reflexes [1]. Despite some controversy in the nomenclature, VS is commonly termed permanent if it persists for longer than 1 year following traumatic injury or 3 to 6 months following anoxic events [5, 6]. Reports of extremely rare late term recovery to higher states of consciousness, however, have led to this qualifier often being dropped.

MCS is similar to VS, though with partial preservation of awareness at drastically reduced levels. Patients may inconsistently be capable of simple command-following, "yes/no" responses, verbalisation or purposeful behaviour. Similar brain activation to healthy controls has been shown in response to painful [7, 8] and emotional [9] stimuli, though exact levels of awareness are unknown. The prognosis in MCS is more varied and slightly better than in VS, though recovery is rare and usually to states with permanent, multiple and severe disabilities [10].

LIS is not a disorder of consciousness as patients in this condition retain normal cognitive capacities. It does, however, have a similar clinical presentation to genuine disorders of consciousness as LIS patients are completely paralysed and unable to speak or move. Most are able to communicate through eye movements [11] though some lack even this capacity; this condition is termed total-LIS. Though discussed mostly as a theoretical possibility, cases have been reported in which clinicians have relied on EEGs to provide evidence for normal consciousness in totally unresponsive patients [12]. Whether these represent true cases of total-LIS, however, is unclear.

Legality of Treatment Withdrawal

Despite remaining publicly controversial, over the past decades the legality of withdrawal of treatment from patients in the VS has been confirmed in the US [13], UK [14] and Australia [15]. This is not currently the case for the more recent diagnosis of MCS. In the court case W v M, believed to be the first of its kind in Britain, a family's application to have treatment withdrawn from a woman in MCS was refused. This verdict has been strongly criticised, due to the ruling's perceived contradiction of M's desires while still competent. These were evidenced by numerous comments that she did not want "a life dependent on others" and would prefer to "go quickly" [16].

Previous Studies of Moral Attitudes

A number of surveys have been undertaken to ascertain the opinions of healthcare professionals towards withdrawal of treatment. These have mostly focused on the VS and have shown majority support for withdrawal of treatment in this condition: levels of support of 66–89 % for withdrawal of treatment from VS patients have been reported amongst healthcare professionals in the US and Europe [17–19]. Some studies have shown that age and religion as well as geographical location (south vs. north Europe) can affect the proportion in favour of withdrawal of treatment [20]. Withdrawal of treatment from MCS enjoys far less support. One study found that only 28 % of healthcare professionals supported withdrawal of treatment in MCS compared with 66 % in VS [19]. In several studies, however, a higher proportion of respondents were willing to choose withdrawal of treatment for themselves than were willing to endorse it as a general policy [19, 21].

Despite surveys as to the views of healthcare professionals, little is known about the views of lay people or the values and underlying factors associated with these beliefs. It is similarly unknown whether the trends found in medical professionals—the propensity for older, more religious physicians to reject withdrawal of treatment; a greater desire to have treatment withdrawn from themselves than to endorse it as a general policy—continue in laypeople.

Hypotheses

We hypothesised that support would be stronger for withdrawal of treatment from the VS and total-LIS than from the MCS or LIS. We also predicted that support for withdrawal of treatment would be higher (a) when the scenario is considered from a first as opposed to third person perspective (b) in those with a lower self-reported religiosity (c) in those who adopted a utilitarian solution to a much studied moral dilemma, "the Footbridge Dilemma" and (d) in those with a higher need for cognition, a standard measure of a motivational tendency to prefer effortful cognition to intuition and gut reaction.

Methods

An online platform, Amazon's Mechanical Turk, was used to recruit US residents to complete a questionnaire comprising attitudes towards withdrawal of treatment, demographic information–age, gender, religion and religiosity–and the Need for Cognition Scale. In order to gain further data on the personality traits that may underlie attitudes to withdrawal of treatment, we also asked participants to take the Big Five Inventory (a general measure of personality) and the Interpersonal Reactivity Index (a standard measure of empathy).

Participants were introduced to the four clinical conditions by descriptions based on clinical guidelines, screened by a neurologist for accuracy. The names of these conditions were substituted for *awak-edness without awareness, minimal awareness, near complete paralysis* and *complete paralysis* to reduce jargon and the effect of connotations associated with 'vegetative'.

Participants responded to 23 questions relating to withdrawal of treatment. This questionnaire was based in part on previous studies, but includes a range of new questions aiming to measure ethical issues not examined by prior research. A 7-point Likert scale was employed to allow participants space to express uncertainty about ethical issues that are complex and difficult.

Participants were first asked to indicate their level of endorsement of the statements: "It is morally acceptable to end the patient's life by stopping treatment in [each of the conditions]" and "I would want to be kept alive if I were in [each of the conditions]".

Then, participants indicated the importance of the following factors in each these decisions: avoidance of suffering, religious beliefs, sanctity of life, dignity, quality of life, interests of family, good of society and the amount of medical resources treatment requires. They also rated the importance of autonomy, best interests, distributive justice, the sanctity of life, the best interests of a patient's family and their religious beliefs in making withdrawal of treatment decisions in general.

The British legal case of W v. M was then briefly described in the form of a short vignette and participants were asked whether withdrawal of treatment was ethical in this particular case.

Finally, participants responded to a widely studied thought experiment, the Footbridge Dilemma. In this dilemma, participants are asked whether it is ethical to push a bystander off a bridge into the path of an oncoming vehicle in order to stop it hurtling towards and killing five others. Responses to this dilemma thus offer a measure of whether individuals favour a 'utilitarian' or 'deontological' approach to hypothetical life and death decisions, enabling us to investigate here whether support for withdrawal of treatment reflects a more general utilitarian tendency.

Quality of responses was ensured by limiting access to the survey to those who had previously completed at least 95 % of their previous Mechanical Turk tasks correctly and by including an 'instructional manipulation check'.¹

Data was processed using SPSS. The seven-point Likert scale was simplified to a categorical answer in response to attitudes towards withdrawal of treatment by assigning a score of 1-2 as agreement, 6-7 as disagreement and 3-5 as having no strong opinion to determine prevalence of agreement with withdrawal of treatment from each of the conditions.

Correlations between agreement with withdrawal of treatment and predictor variables such as religiosity, performance on personality tests, decision in the Footbridge Dilemma and endorsement of a series of ethical principles was calculated using the Pearson Correlation Co-efficient. Friedman Two Way Analysis of Variance and Wilcoxon Signed Rank Tests were used to determine significance of differences in the case of each variable. Results were considered significant at P < 0.05.

Ethics

Ethics approval was obtained from the University of Oxford Social Sciences and Humanities Inter-Divisional Research Ethics Committee and the Monash University Human Research Ethics Committee. Participation was anonymous, voluntary and restricted to those over the age of 18.

Results

Two hundred forty-one valid responses were received of which 42 were excluded for failing the 'instructional manipulation check' (see above), leaving a study sample of 199. The mean completion time of the survey was 20 min and 30 s.

Support for withdrawal of treatment from VS and total-LIS was higher than MCS or LIS (Table 1). There was a marked difference between the levels of support for withdrawal of treatment when considered from a first

 Table 1 Responses to question 'it is morally acceptable to end the patient's life by stopping treatment in [each of the conditions]'

	Agree	Unsure/no strong opinion	Disagree		
VS	40.2 %	42.2 %	17.6 %		
MCS	20.6 %	38.2 %	41.2 %		
LIS	25.3 %	38.9 %	35.8 %		
Total-LIS	35.2 %	38.2 %	26.6 %		

Here, a score of 1 or 2 on the Likert scale was defined as agreement, 3-5 as unsure or no strong opinion and 6 or 7 as disagreement

and third person perspective (Table 2). Wilcoxon signed rank tests showed participants were more likely to want treatment removed from themselves than to endorse it in general in VS (Z=-6.056, P<0.001), MCS (Z=-6.746, P<0.001), LIS (Z=-6.681, P<0.001) and total LIS (Z=-5.740, P<0.001).

The presence of consciousness was considered the most important factor in withdrawal of treatment decisions, followed by considerations of autonomy and the ability to interact with others. Considerations of religion, the sanctity of life and longevity of the patient were considered least important. In terms of the principles set out by Beauchamp and Childress, autonomy was considered more important than best interests and much more than distributive justice (Table 3).

Considerations of distributive justice, autonomy, best interests and the patient's suffering, dignity and quality of life were positively correlated with endorsement of withdrawal of treatment. Religiosity and endorsement of the sanctity of life were negatively correlated (Table 4). Older subjects were more strongly opposed to withdrawal of treatment, but only from total-LIS (r=-0.145, P=0.041).

 Table 2 Responses to question 'I would want treatment withdrawn if I were in [each of the conditions]'

	Agree	Unsure/no strong opinion	Disagree		
VS	64.2 %	21.7 %	14.1 %		
MCS	41.4 %	36.4 %	22.2 %		
LIS	35.8 %	38.9 %	25.3 %		
Total-LIS	55.8 %	27.1 %	17.1 %		

Here, a score of 1 or 2 on the Likert scale was defined as agreement, 3–5 as unsure or no strong opinion and 6 or 7 as disagreement

¹ An instructional manipulation check allows researchers to identify participants who are not actively engaging with a questionnaire. A paragraph telling participants to select a non-obvious response is followed by a question with a seemingly obvious answer. Those who selected the seemingly obvious answer showed themselves to be skipping instructions and so were excluded from the survey. These have been shown to increase the validity of responses [22].

Table 3 Endorsement of factors important in withdrawal of treatment decisions 1 = not at all important... 7 = very important

Values/factors	Mean	Median		
Autonomy	6.18	7		
Best interests	5.72	6		
Distributive justice	3.82	4		
Sanctity of life	3.19	3		
Best interests of family	4.24	5		
Religion	3.22	3		
Presence of consciousness	6.59	7		
Avoidance of suffering	5.83	6		
Dignity	5.82	6		
Ability to interact with others	6.10	7		
Longevity	2.20	1		

Forty-seven percent disagreed with the courts decision against withdrawal of treatment in W v. M, more than twice the 22.8 % who agreed with it (Table 5). Support for withdrawal of treatment in this case was inversely correlated with religiosity (r=0.288, P>0.001).

There were 76.9 % of the participants rejected the utilitarian solution to the Footbridge Dilemma. Older respondents were less likely to agree with a utilitarian decision in this case. There was no correlation between responses to the Footbridge Dilemma and religiosity or the personality traits we measured (Table 6). Interestingly, and only partly in line with our hypothesis, endorsement

 Table 4
 Endorsement of factors correlated with endorsement of treatment withdrawal in all four conditions

Factor	Pearson correlation coefficient	Statistical significance (2-tailed)		
Positive correlation				
Distributive justice	0.455	< 0.001		
Patient suffering	0.415	< 0.001		
Dignity	0.470	< 0.001		
Quality of life	0.565	< 0.001		
Autonomy	0.328	< 0.001		
Best interests	0.236	0.001		
Negative correlation				
Religiosity	-0.272	< 0.001		
Sanctity of life	-0.519	< 0.001		
No correlation				
Best interests of family	0.088	0.219		

 Table 5
 Responses to question 'should treatment be stopped [in case of M]'

Agree	47.0 %
Unsure/no strong opinion	30.3 %
Disagree	22.7 %

Here, a score of 1 or 2 on the Likert scale was defined as agreement, 3–5 as unsure or no strong opinion and 6 or 7 as disagreement

of the utilitarian solution was correlated with endorsement of withdrawal of treatment in MCS (r=.220, P= 0.002), LIS (r=0.199, P=0.005) and total-LIS (r=0.139, P=0.050) but not in VS (r=-0.007, P=0.923).

Contrary to our hypothesis, higher 'need for cognition' wasn't generally correlated with greater endorsement of withdrawal of treatment, nor, contrary to some prior studies, was it correlated with utilitarian responses to the Footbridge Dilemma. Those with a higher need for cognition were less likely to want withdrawal of treatment from themselves in LIS (r=-0.184, P=0.015), though not in any other condition. They were also less likely to endorse distributive justice in withdrawal of treatment decisions (r=-0.234, P=0.002).

There was no correlation between scores on the interpersonal reactivity index and withdrawal of treatment in any of the four cases or with decisions in the Footbridge Dilemma.

Discussion

We found that lay attitudes towards withdrawal of treatment differ depending on individuals' religiosity

Table 6	Endorse	ement	of f	actors	in	withdr	awal	of 1	trea	tment
decision-	making	correl	ated	with	util	itarian	decis	ion	in	Foot-
bridge Di	ilemma									

Factor	Pearson correlation coefficient	Statistical significance (2-tailed)
Positive correlation		
Distributive justice	0.208	0.003
Patient suffering	0.150	0.036
Quality of life	0.149	0.037
Negative correlation		
Age	-0.144	0.042
No correlation		
Religiosity		

and values. They do not, however, appear to be associated with underlying personality traits. Withdrawal of treatment is seen as more acceptable for patients in VS or total-LIS than LIS or MCS, though there is a large amount of variability in attitudes. In line with previous research, individuals are more likely to want treatment withdrawn from themselves than endorse withdrawal of treatment more generally.

Attitudes Towards Withdrawal of Treatment

At first, our results appear discordant with previous surveys, which have shown much higher levels of support for withdrawal of treatment from VS. Surveys done in the US found levels as high as 80–89 % [17, 18], compared with 40.2 % found here. This seems largely due to methodological differences. Previous surveys relied on a forced yes/no dichotomy, unlike the Likert scale used here, where participants were given the option of indicating that they were unsure. One striking finding is that when people are given this option, a large proportion, approximately 40 %, select it in each case. Clearly there is a lot of uncertainty that has been somewhat obscured by the methodology of prior studies. It is likely that this indecision reflects hesitancy endorsing or rejecting withdrawal of treatment categorically and is a recognition that it may be appropriate in some instances though not all. This view is supported by the lower level of uncertainty (30 %) when withdrawal of treatment is considered in the single case of W v. M. Furthermore, previous studies directly referenced the vegetative and minimally conscious states by their proper names, unlike the substituted names used here.

A slightly lower level of support for withdrawal of treatment may also be explained by different demographics. Previous research concerned medical professionals who presumably have much greater familiarity with withdrawal of treatment. For these professionals, even hypothetical cases are therefore more real and vivid which may be a factor leading to greater acceptance. A previous study, including both physicians and paramedical professionals, found 66 % in agreement [19], lower than the 89 % of physicians quoted above. Greater unwillingness to withdraw treatment as we move from physicians to lay people does therefore seem to be a consistent finding.

The higher level of support when withdrawal of treatment is considered from the first as opposed to third person perspective confirmed one of our hypotheses and reflects previous research [19, 23]. In each case a large proportion were still uncertain about the morality of withdrawal of treatment, though this proportion halved when withdrawal of treatment was considered from the first person perspective in the case of VS. This was not the case for MCS, where the proportion who were unsure remained steady. The proportion who rejected withdrawal of treatment in this case, however, halved, while those who supported it doubled. It does therefore seem that when withdrawal of treatment is considered from this perspective there is a movement of most along the spectrum from rejection to support.

This difference may also be due to order effects. Participants were first asked whether withdrawal of treatment is ethically acceptable, and only then whether they would want it in their own case. The latter is less abstract and more vivid, which may have led to participants reaching different moral conclusions.

In any event, since it is unlikely that participants both wanted withdrawal of treatment in their own case *and* thought that withdrawal of treatment is ethically wrong even when such wishes have been expressed, we can conclude that lay people accept the permissibility of withdrawal of treatment in brain damaged patients to much higher levels than is revealed by direct questioning, though they may still have reservations about accepting withdrawal of treatment as a general policy.

W v. M

Our results suggest that common criticism of this legal decision is in line with the moral attitudes of lay people. More than twice the number of respondents supported withdrawal of treatment in this case than rejected it. This could, however, represent a cultural difference given that the US, from which we drew our sample, bases court decisions on autonomy via a substituted decision rather than best interests using a balance sheet approach as in the UK.

Interestingly, a much higher proportion endorsed withdrawal of treatment in the case of M (47 %) than from MCS in general (20.6 %). Importantly, this may indicate that, even though some personally disagree with withdrawal of treatment, the strong consensus about the importance of autonomy requires that they accept it so long as it directly reflects the patient's wishes. The hesitancy to endorse withdrawal of treatment more generally may therefore be an indication that the current safeguards to ensure decisions are autonomous are seen to be

inadequate or indeed that lay people are ignorant of those safeguards that presently exist. Clearly the role of advance directives and other devices in upholding patient autonomy need to be emphasised.

The much higher rate of support for withdrawal of treatment in the case of W v. M than for MCS more generally also supports our suggestion that agreement with withdrawal of treatment increases when the condition is considered more vividly, and not just from a first as opposed to third person perspective.

Correlates of Endorsement of Withdrawal of Treatment

Unsurprisingly, given traditional antagonism towards withdrawal of treatment from religious quarters, we found an inverse correlation between religiosity and agreement with withdrawal of treatment.

This indicates that there is a strong religious component to some opposition to withdrawal of treatment in these conditions. Given the potential for public opinion to shape public policy, religiously motivated moral beliefs may legitimately be questioned when they impact on secular society. Religiously motivated opposition to withdrawal of treatment may therefore be given less weight.

It is not surprising that different principles and frames of references are associated with support and opposition to withdrawal of treatment. It is unclear, however, whether the values endorsed by participants shape the ethical decisions they make, or were endorsed as later rationalisations for moral beliefs they held independently, perhaps on an intuitive or emotional basis. If the former is correct, then these results suggest that attempts to promote the acceptance of withdrawal of treatment should emphasise the importance of the principles of distributive justice, autonomy and best interests and considerations of the patient's suffering, dignity and quality of life–all of which are factors positively correlated with increased acceptance of withdrawal of treatment.

Personality Traits

The personality traits that we measured did not have a strong or consistent effect on moral attitudes. Other factors, such as a person's religiosity or the values they endorse as being important in decision-making appear to have a much greater role in shaping ethical beliefs. This suggests that ethical values are not mere artefacts of personality traits and instead represent genuine personal dimensions that are capable of influencing decision making. Interestingly, higher need for cognition wasn't correlated with greater endorsement of withdrawal of treatment, suggesting that opposition to withdrawal of treatment isn't based on mere gut responses or intuition and that, conversely, support for withdrawal of treatment isn't necessarily based on greater degrees of critical moral reflection.

Values Associated with Support for and Opposition to Withdrawal of Treatment

Several factors, such as autonomy and the presence of consciousness have very broad appeal as significant factors in moral decision making.

The low level of endorsement of distributive justice as an important factor in attitudes to withdrawal of treatment is significant given the pre-eminence of considerations of justice in contemporary bioethics. This could reflect an inability to take account of the wider societal impacts of treatment decisions or, alternatively, unwillingness to place a price on life.

The latter interpretation is congruent with our results in the Footbridge Dilemma. 76.9 % rejected a utilitarian solution to this dilemma. This figure is broadly in line with prior research, though some studies reported higher rates of non-utilitarian responses [24].

This result suggests lay people reject utilitarian cost-benefit analyses as an appropriate consideration in life and death decisions, both in the context of hypothetical dilemmas such as the Footbridge Dilemma as well as in real life medical cases relating to withdrawal of treatment in brain damaged patients. This represents a departure from the views of a number of medical and ethical experts [25, 26]. For instance, Jennett, one of the first to describe VS, believes we "certainly should question the utilisation of precious resources [for treatment of disorders of consciousness]" and that we "can no longer afford the luxury of always doing everything for every patient" [27]. Our findings suggest that emphasis on such considerations is unlikely to have much sway on popular opinions about withdrawal of treatment.

Conclusion

The present study was novel in its focus on the moral views of lay people, as opposed to healthcare professionals, and also in its examination of the underlying factors that may affect these views.

Here, we found that, though opposition to withdrawal of treatment in the cases of MCS and LIS appears significant, its strength and nature are open to question. This is highlighted by the increased proportion in favour of withdrawal of treatment when considered in concrete cases, such as that of W v. M, or from a first rather than third person perspective. This suggests that support (or at least acceptance) of withdrawal of treatment is considerably stronger than suggested by prior surveys, though comparisons are difficult due to the large number of unsure participants.

Support for withdrawal of treatment was most strongly associated with endorsement of the importance of patient autonomy, dignity, suffering, best interests and distributive justice. Emphasising the importance of these values may lead to increased acceptance of withdrawal of treatment. Importantly, considerations of distributive justice were not rated as important by many respondents, nor was a utilitarian solution generally supported in the Footbridge Dilemma. This suggests that a majority rejects utilitarian cost-benefit analyses in life and death decisions. The lack of association between personality measures and endorsement of both withdrawal of treatment and different ethical values indicates that moral beliefs are not reducible to personality traits.

This study has several limitations. People may not always have accurate introspective access to the factors that really drive their moral views, and it is difficult to convey complex clinical and ethical notions in a survey form. A move to focus groups may therefore provide an important source of further evidence about lay attitudes to withdrawal of treatment. Another inherent limitation to this sort of cross-sectional study design is the inability to establish a temporal relationship and therefore causality. Therefore, there is no way of knowing whether the values participants considered important in decision-making are the foundations of those decisions or simply rationalisations of them.

One issue that seems urgent to clarify is the apparent inconsistencies in opposition to withdrawal of treatment. This is evident in the gap between first and third person judgement in these decisions and also in the much higher rate of endorsement of withdrawal of treatment in the W v. M case than in MCS generally. Future research should elucidate how people justify these discrepancies, which this study cannot fully resolve. Acknowledgments The authors would like to thank Prof Canny for his support. Research was partially funded by a bursary from Monash University and the manuscript was made open access with the kind support of the Wellcome Trust (Grant 086041/Z/08/Z). The authors declare no conflicts of interest.

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