

# How the public responded to the Schiavo controversy: evidence from letters to editors

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Received 13 May 2010

Accepted 17 May 2010

## ABSTRACT

The history and genesis of major public clinical ethics controversies is intimately related to the publication of opinions and responses in media coverage. To provide a sample of public response in the media, this paper reports the results of a content analysis of letters to editors published in the four most prolific American newspapers for the Schiavo controversy. Opinions expressed in the letters sampled strongly supported the use of living wills and strongly condemned public attention to the case as well as political interventions. Letters tended to be against withdrawal of life support, proxy consent and associated procedures as well as against court decisions and legal procedures. In comparison with reports written by journalists, letters to editors contained fewer controversial claims about Schiavo's neurological condition and behavioural repertoire but similar loaded language to describe withdrawal of life support. Distinct public discourses can be encountered in different stakeholders suggesting complex and extensive pluralism even within the media.

The history and genesis of major public clinical ethics controversies (eg, Quinlan, Cruzan, Schiavo) is intimately related to the publication of opinions and responses in media coverage.<sup>1</sup> It is difficult to pinpoint the specific impact of content conveyed in the media in such complex cases. Nonetheless, it is clear that media coverage and public responses can have important implications as illustrated by political interventions to restrict withdrawal of life support practices occurring both before and after the publicly debated death of Terri Schiavo.<sup>2</sup> To date, public responses and the activities of the media in major public clinical ethics controversies have not been well examined empirically. To provide a sample of public response in media coverage, we report the results of a content analysis of letters to editors published in the four most prolific American newspapers during the Schiavo controversy.

## METHODS

We used the guided news search function of the LexisNexis academic database with keyword searches to find letters to editors about the case of Terri Schiavo published in American print media from 1990 to 2005. We selected the four newspapers with the most prolific coverage of the case and available in LexisNexis based on a previous study, and we collected reader correspondence published in these media sources.<sup>3</sup> All letters were coded by

a first coder (MK) and reviewed by a second coder (MS). Disagreements in coding were settled by discussion and consensus agreement with the principal investigator (ER). Coding was based on the instructions contained in a coding guide modelled on a previous study of journalist reports of the Schiavo case.<sup>3</sup> The coding structure included the identification of: (1) author characteristics (eg, gender; profession); (2) topics featured in the headline (eg, legal; political); (3) description of Schiavo's neurological condition (eg, persistent vegetative state, brain injury); (4) description of Schiavo's behavioural repertoire (eg, 'is aware', 'responds'); (5) description of withdrawal of life support in the Schiavo case (eg, 'murder', 'peaceful death') and (6) opinions regarding salient topics in the Schiavo controversy (eg, withdrawal of life support; legislative and political action). Opinions identified for item 6 were coded as being for, against or equivocal regarding each salient topic (eg, for withdrawal of life support; against withdrawal of life support; equivocal regarding withdrawal of life support). We also coded claims in items 3, 4 and 5 with regard to their stance (eg, affirmation that Terri Schiavo is in a vegetative state; refutation that she is in a vegetative state; equivocal about her vegetative state diagnosis). We used descriptive statistics to characterise the composition and properties of the sample and we assessed the accuracy of the descriptions of Schiavo's neurological condition, behaviours and prognosis based on common medical understandings of the vegetative state.<sup>4,5</sup> We conducted further statistical analysis to examine any statistical differences ( $p \leq 0.05$ ) between 'elite' news coverage (*Washington Post* and *New York Times*) and regional sources (*Tampa Tribune* and *St Petersburg Times*). We conducted Fisher's exact test to see if there was an association between the newspaper groups and the positions published (eg, in favour, against, equivocal) jointly and then, when the Fisher's test suggested differences we conducted sample tests of proportions to see if the two groups had equal proportions of positions published or not (eg, in favour, against, equivocal).

## RESULTS

We found a total of 451 published letters to editors in the *St Petersburg Times* (N=178; 39%); the *Tampa Tribune* (N=175; 38%); the *New York Times* (N=81; 18%) and the *Washington Post* (N=17; 4%). Most letters were first published in 2005 (N=338; 75%) and in 2003 (N=85; 19%). The first letters were published in the *St Petersburg Times* and in the

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*Tampa Tribune* in 2000. Only in 2003 were letters published in the *New York Times* and in 2005 in the *Washington Post*. The professions of authors were unknown in 87% (N=394) of cases. Among the authors who declared their profession: 20 (4%) were identified as physicians; 18 (4%) as lawyers; 17 (4%) as politicians; 14 (3%) as other healthcare providers; eight (2%) as university faculty and three (1%) as bioethicists. The majority of authors were male (N=230; 51%) as opposed to female authors (N=173; 38%). The gender of 48 (11%) authors was not identifiable with confidence (eg, anonymous, ambiguous first name). Headlines focused on end-of-life and ethical aspects (N=85; 19%); legal aspects (N=71; 16%) and political aspects (N=62; 14%) of the case. A few articles included claims that Schiavo had a poor prognosis (N=13; 3%), a good prognosis (N=6; 1%) and a few articles included equivocal claims regarding her prognosis (N=8; 2%).

Opinions expressed in letters strongly supported the use of living wills and strongly condemned media and public attention to the case as well as political and legislative interventions (table 1). Opinions in letters tended to be against withdrawal of life support, proxy consent and associated procedures as well as court decisions and legal actions. Table 1 also shows that many claims regarding Schiavo's neurological condition supported that she was in a vegetative state and only a few refuted this widely accepted diagnosis.<sup>3</sup>

Table 2 shows that the behavioural repertoire of Schiavo was not the object of extensive comments and discussion, although there were a few claims (inconsistent with the vegetative state diagnosis) that she exhibited meaningful behaviours and a few claims (consistent with the vegetative state diagnosis) that she

did not exhibit meaningful behaviours. We found that many controversial terms were used to describe withdrawal of life support in the Schiavo case such as 'death by starvation', 'murder' and 'euthanasia' (table 2).

## DISCUSSION

We found that letters published by the *St Petersburg Times*, the *Tampa Tribune*, the *New York Times* and the *Washington Post* peaked in 2003 and 2005 similar to the evolution of media reports on the Schiavo case.<sup>3</sup> Opinions expressed in letters appear both to coincide and depart from the results of American public opinion surveys conducted after Terri Schiavo's death.<sup>6</sup> These surveys suggested that a small majority of the public was opposed to various forms of political and judicial interventions (except those from the federal and supreme courts). These survey findings are consistent with the opinions expressed in the letters to editors we analysed, although the letters in our study were more clearly against political and judicial interventions. Letters in elite sources were also more frequently against political and legislative actions. However, the letters differ from published surveys because they featured, proportionally speaking, more disapprovals of withdrawal of life support and of the proxy consent process (eg, Michael Schiavo's role and decisions) than the opinions found in published surveys.<sup>7</sup> The interpretation of this discrepancy is complex. Writers of letters could have specific motivations and opinions to voice that differ from national trends or the newspapers we analysed could assemble readerships that do not represent national averages.

In comparison to reports on the Schiavo controversy, which stressed debates about Schiavo's prognosis and included frequent

**Table 1** Opinions expressed regarding various aspects of the Terri Schiavo case and description of Schiavo's neurological condition

Opinions regarding various aspects of Terri Schiavo case			
	In favour (%)	Against (%)	Equivocal (%)
Living wills	73 (16)	3 (1)	3 (1)
Withdrawal of life support	69 (15)	94 (21)	15 (3)
Court decision and legal procedure	36 (8)	52 (12)	5 (1)
Legislative and political intervention	31 (7)	153 (34)†	7 (2)
Proxy consent and proxy procedure	15 (3)	30 (7)	11 (2)
Media and public attention dedicated to case	7 (2)	90 (20)	4 (1)
Descriptions of Terri Schiavo's neurological condition			
	Affirmation (%)	Refutation (%)	Equivocal (%)
Vegetative state	22 (5)	2 (0)*	1 (0)
Brain damage	9 (2)	—	—
Persistent vegetative state‡	7 (2)	1 (0)*	3 (1)
Irreversible vegetative state	7 (2)	—	—
Brain is destroyed	5 (1)	—	—
Coma or coma-like§	3 (1)	3 (1)	—
Brain injury	2 (0)	—	—
Severe brain damage	2 (0)	—	—
Brain is gone	1 (0)	—	—
Extensive brain damage	1 (0)	—	—
Brain death	1 (0)*	1 (1)	—

\*Statement inconsistent with the vegetative state diagnosis.

†Statistical difference ( $p \leq 0.05$ ) between 'elite' and 'regional' sources with more frequent opinions 'against' in elite sources.

‡Schiavo was diagnosed as being in a vegetative state. However, as Bernat writes, '[t]he terminology of the vegetative state has been plagued with confusion since it was coined. The modifiers 'persistent' and 'permanent' cause ambiguity. (...) it is best to use the term 'VS' as a diagnosis without a preceding modifier such as persistent or permanent' (p 289).<sup>5</sup> However, in the period under study, the *N Engl J Med* Task Force specified that '[t]he adjective "persistent" refers only to a condition of past and continuing disability with an uncertain future, whereas "permanent" implies irreversibility. Persistent vegetative state is a diagnosis; permanent vegetative state is a prognosis.'<sup>4</sup> Accordingly, the Task Force continuously referred to the 'persistent vegetative state' without clear implications with regards to prognosis. Many commentators described Schiavo as being in a 'persistent vegetative state' following the Task Force's usage. In our study, we were examining media coverage from the early 1990s to the middle of the 2000s, a period in which there was even less clarity about the diagnostic and prognostic meaning of terminology and in which medical commentators also used the 'persistent vegetative state' following a diagnostic (non-prognostic) meaning. We felt like it was fair to accept 'persistent vegetative state' as an acceptable description of Schiavo's neurological condition in media coverage even though some may rightly consider that she was more accurately in a 'permanent vegetative state'.

§Although not false strictly speaking, the term coma is an inaccurate description of the vegetative state because coma and the vegetative state are distinct diagnoses.<sup>5</sup>

**Table 2** Descriptions of Terri Schiavo's behavioural repertoire and withdrawal of life support

Behaviour	Affirmation (%)	Refutation (%)
Disabled	8 (2)	—
Incapacitated	7 (2)	—
Breathes	7 (2)	—
Aware or alert	3 (1)†	3 (1)
Feels (has feelings)	3 (1)†	1(0)
Smiles	2 (0)‡	—
Conscious	1 (0)†	4 (1)
Discomfort (feels)	1 (0)†	1 (0)
Pain (feels)*	1 (0)†	—
Wakeful or awake	1 (0)‡	—
Cries	1 (0)‡	—
Sees	—	7 (2)
Talks or pronounces words	—	5 (1)
Responds	—	2 (0)
Communicates	—	1 (0)
Cognitive function (has)*	—	1 (0)
Swallows, can eat or drink	—	1 (0)

  

Description of withdrawal of life support	Affirmation (%)	Refutation (%)
Death by starvation	46 (10)	4 (1)
Murder	23 (5)	4 (1)
Deprivation of food or water	14 (3)	1 (0)
Death by dehydration	6 (1)	1 (0)
Euthanasia	6 (1)	—
Death sentence	4 (1)	—
Elimination or extermination	4 (1)	—
Barbaric act	4 (1)	1 (0)
Painless, peaceful, comfortable death	4 (1)	3 (1)
Against God or religion	3 (1)	—
Physician assisted suicide	2 (0)	—
Felony or crime	1 (0)	—
Death with dignity	—	4 (1)

\*Only one equivocal claim regarding this behaviour.

†Claim is inconsistent with standard understandings of the vegetative state.<sup>4 5</sup>

‡Ambiguous claim that could signify an affirmation or refutation of meaningful behaviour.

misattribution of conscious behaviours to Schiavo,<sup>3</sup> letters to editors did not extensively discuss Schiavo's prognosis and did not frequently feature erroneous claims that Schiavo exhibited meaningful behaviours (eg, she is aware, she responds). Letters also contained fewer controversial claims about Schiavo's neurological condition and behavioural repertoire than reports written by journalists. For example, claims refuting a persistent vegetative state diagnosis for Schiavo were less frequent in letters (1%) than in actual reports written by journalists (6%).<sup>3</sup> Letters included loaded language similarly to reports to describe withdrawal of life support. These are surprising findings because many letters featured opinions against withdrawal of life support, and one would expect those letters to rely on erroneous attributions of meaningful behaviour and false beliefs about

Schiavo's neurological condition. These findings support the interpretation that reports (even in comparison to letters with a pro-life overtone) played an active role in fuelling the Schiavo controversy by frequently featuring erroneous statements and divided opinions on Schiavo's prognosis, behavioural repertoire and neurological condition.<sup>8</sup>

We believe that this examination of letters to editors and of the discourse on the vegetative state in the Terri Schiavo case provides interesting insights into the nature and genesis of the Schiavo controversy. In combination with content analysis of reports<sup>3</sup> and public opinion surveys,<sup>7</sup> the analysis of reader letters suggests the existence of distinct public discourses in different stakeholders (journalist reports, public opinion in survey responses, letters to editors). This in return suggests that public debates about controversial clinical cases surface in a complex environment marked by extensive pluralism even within the media.<sup>9</sup> There are limitations to our study because it does not reflect national American responses to media coverage and captures only some of the most salient and prolific sources of media coverage on the Schiavo controversy. Further research should explore the structure of public discourse in public clinical ethics controversies to increase our understanding of the media's content in these cases and help assess the impact of its content on healthcare policies as well as on the attitudes and behaviours of patients and providers.

**Acknowledgements** The authors would like to thank Zoë Costa-von Aesch, Amaryllis Ferrand, Vivian Chau, Lila Karpowicz and Aline Tabet for their assistance as well as Dr Emily Bell and Cynthia Forlini for feedback. Special thanks go to Nathalie Prud'homme for inspiring the idea of this study.

**Funding** Support for this research comes from the Institut de recherches cliniques de Montréal (ER), the Social Sciences and Humanities Research Council of Canada (ER), the Canadian Institutes of Health Research (ER), the Greenwall Foundation (JI) and NIH/NINDS R01 #NS045831-04 (JI).

**Competing interests** None.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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*J Med Ethics* published online August 6, 2010

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