

Running head (no more than 40 character spaces): Voting and TBI

Title: Qualitative Examination of Voting Empowerment and Participation Among People Living with Traumatic Brain Injury

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1 **Title:** Qualitative Examination of Voting Empowerment and Participation Among People
2 Living with Traumatic Brain Injury

3

4 **Abstract**

5 **Objective:** To examine political participation following traumatic brain injury (TBI).

6 **Design:** Qualitative, participatory research via interviews and observations.

7 **Setting:** Community.

8 **Participants:** 57 individuals with history of TBI and 28 family members (total 85).

9 **Procedures:** Each participant was interviewed to discuss their experience of voting in 2007 or
10 2008. Data were coded using Grounded Theory to develop themes, metacodes, and theories.

11 **Measures:** not applicable.

12 **Results:** Four themes emerged from the data: 1) People with TBI have barriers to voting; 2) The
13 voting process can be improved for people with TBI; 3) Voting is the responsibility of members
14 of society; 4) Voting is one way we have a voice in society.

15 **Conclusions:** The data support the importance of voting as an American right regardless of the
16 presence of disability. While persons with TBI report voting represents their freedom and voice,
17 there may be barriers that can threaten or limit their voice.

18

19 **Key words:** brain injuries, politics, qualitative research, community participation

20

21 **Abbreviations:**

22 CAT-V Competency Assessment Tool for Voting

23 MMSE Mini-mental state examination

24 TBI Traumatic brain injury

25 US United States

26

27 Voting is the most basic means of political expression in a democratic society. For
28 individuals with disabilities, voting is even more vital because their “life, liberty and pursuit of
29 happiness” may depend upon laws, statues, and public services enacted and managed by elected
30 officials that their non-disabled counterparts take for granted. Yet, data indicate people living
31 with disability vote less often than those without.^{1,2} Many efforts have been implemented to
32 improve voter participation among individuals with disability.³ After several years of decline, the
33 2018 United States (US) midterm election experienced an increase in disability voter turnout by
34 8.5 percentage points compared to 2014.² Despite this increase, there remains a 4.7-point turnout
35 gap between those with and without disabilities, representing 2.35 million more votes by people
36 with disabilities if voting rates were equal.² A variety of barriers may contribute to lower
37 disability turnout⁴ including transportation access, voter identification laws, long lines,
38 inaccessible polling places, voting machines, or the ballot. In 2016, the General Accounting
39 Office found that 60% of polling places reviewed have at least one impediment to voters with
40 disabilities.⁵

41 The disability turnout gap in US elections is especially striking among people with
42 cognitive impairments. Voter turnout among those with cognitive impairment was 43.5%
43 in 2016 compared to 62.2% among people without disabilities (-18.7 points).^{2,4} The
44 voting rates were lower for both groups in the 2018 midterm elections (37.1% and 54.0%
45 respectively), but the disability gap was similar (-16.9 points).

46 Although researchers have studied voting among individuals with disability at
47 large, scholars still know little regarding the experience, thoughts, and feelings of voting
48 and political participation from the perspective of individuals living with traumatic brain
49 injury (TBI). A conservative estimate is that 3.2 million Americans (1.1% of the US population)

50 are living with disability attributable to TBI.^{6,7} TBI may result in a range of impairments in
51 physical, sensation, perception, communication, cognitive, emotional and behavioral
52 function that may complicate participation in the voting processes in both overt and
53 subtle ways. TBI typically results in difficulty with memory, planning, initiation, cognitive
54 flexibility, and decision-making,⁸ which may create challenges in complex activities such as
55 voting. TBI may cause impaired hearing and vision, and may limit one's access to
56 transportation. Aspects of voting may pose accessibility challenges, including navigating
57 physically, ballot design (legibility, consistency, and the organization and presentation of
58 information), and the technologies used for voting.⁹ Yet, little is known about the experience
59 of and obstacles to voting participation following TBI.

60 In a convenience sample of 51 registered voters with TBI (a subset of the current study),
61 Hirsch and colleagues¹⁰ found statistically significant differences in voting "competence" of
62 participants with TBI who voted and participants with TBI who did not vote in the 2007 and
63 2008 elections held in Mecklenburg County, North Carolina, US. Voting among individuals with
64 TBI was predicted by higher Competency Assessment Tool for Voting (CAT-V) total score, and
65 older age, while being married was inversely related to voting. Traditional predictors of voting in
66 the general population (education, being married, not living alone, Presidential election) were not
67 predictors among this TBI group. The authors suggested individuals with TBI may value voting,
68 but a partner may discourage a person with TBI from voting. In terms of education, with TBI,
69 competence to vote may be more important to the decision to vote than having formal education.
70 Qualitative data will shed additional light on these questions.

71 Ethical, legal and societal considerations exist regarding voting by persons with cognitive
72 impairment due to dementia, or other cognitive impairment conditions.¹¹⁻¹³ Comparing 14

73 individuals with TBI to 22 non-injured college students, Link, et al.¹⁴ found voting competence
74 (measured by the CAT-V) and political knowledge (election-specific knowledge and correct
75 responses on United States Citizen and Immigration Services citizenship exam questions) to be
76 similar across groups.

77 A view into the experiences of voting among people living with TBI will help
78 identify barriers and facilitators of voting, and inform the development of strategies to
79 optimize participation. The present study uses qualitative and participatory research (PR)
80 methods to study the experience of voting among persons living with TBI through semi-
81 structured interviews and qualitative observation at polling places. The study objectives are to: 1)
82 discover and delineate how persons with TBI and other stakeholders experience political
83 participation; and 2) assess possible voting disenfranchisement.

84

85 **Methods**

86 *Choice for Analytical Method:* Qualitative research methods with a PR approach was deemed the
87 most appropriate design for this early stage research into political participation following TBI.
88 Qualitative research methods are advantageous¹⁵⁻¹⁷ for researching sensitive or taboo subjects or
89 for obtaining detailed descriptions of incompletely understood and complex problems (such as
90 political empowerment and voting).¹⁸ Findings from qualitative research assist with theory
91 development and hypothesis generation and testing. PR engages the people studied (people with
92 TBI) and their advocates as collaborators in all aspects of the research.¹⁹ Many scholars use PR
93 designs in applied disability and rehabilitation science,²⁰⁻²² opening a view into the lives of
94 individuals affected by the issue studied.²³⁻²⁴

95 *Participatory Research Approach:* Following PR principles,²⁵ stakeholders significantly
96 participated in (a) determining study focus and which questions to ask, (b) analyzing data, and
97 (c) confirming validity through member check. The research team included a community-based
98 PR advisory council comprised of a variety of relevant stakeholders—5 university researchers, 8
99 medical researchers and healthcare providers, 4 community members, and 2 people with TBI and
100 2 close relatives of people with TBI. The initial research team consisted of two university
101 researchers, two medical researchers, and two family members of people with TBI.

102 *Participants:* The research team identified potential study participants through a registry of
103 individuals who previously received inpatient rehabilitation for TBI. Eligibility criteria for this
104 registry include: age at least 16 years at time of injury; moderate-severe TBI [defined as post-
105 traumatic amnesia greater than 24 hours, trauma-related intracranial neuroimaging abnormalities,
106 loss of consciousness exceeding 30 minutes, or Glasgow Coma Scale score (GCS) in the
107 emergency department of less than 13]; and received acute care hospitalization within 72 hours
108 followed by inpatient rehabilitation. At the time of the study, this registry held 782 names.
109 Following institutional review board approval, we conducted telephone screening of 129 persons
110 with TBI (consecutively selected when due for their follow-up interview). For the participants
111 with TBI, the inclusion criteria for the present study consisted of: US citizen, ≥ 18 years old, TBI
112 ≥ 6 months prior to election day, registered to vote and voted at least once in the previous three
113 elections; and for family members - U.S. citizen, ≥ 18 years old, in an interacting relationship
114 with the TBI survivor.

115 *Setting and Procedure:* The study took place in Charlotte, North Carolina. Through a
116 participatory process with a community-based PR advisory council, the research team developed
117 a qualitative interview targeted to learn about experiences with voting in Mecklenburg County,

118 Charlotte, NC, US following the May 2007 and November 2007 elections and 2008 presidential
119 election. Trained research assistants administered the interview (Appendix A), and mini-mental
120 state exam (MMSE).²⁶ Research assistants accompanied a subset (n=21) of participants to the
121 polls and took detailed field notes of their experience.

122 *Data analysis:* Interview audio-recordings and field notes were transcribed and then coded using
123 hyperRESEARCH software (Researchware, inc) in a Grounded Theory process.^{27,28} Raw data
124 were categorized into themes using an inductive method in which we observed patterns in the
125 data and took into account the relationships between the data and the categories through a
126 constant comparison process. The codes and categories were mutable until late in the analysis.
127 After an initial, open, coding step, followed by a selective coding step, our next step was to
128 integrate our coding categories in order to determine conceptual relationships between and
129 among various categories. To ensure the process met the criteria of confirmability and
130 credibility, data coding followed the following procedures: 1) each researcher coded
131 independently; 2) pairs of university and medical researchers discussed and resolved
132 discrepancies; 3) the researcher group as a whole reviewed the emergent themes to combine and
133 collapse the codes into hierarchical categories, or metacodes. Emergent theories, or explanations,
134 began to emerge. Credibility was determined by data triangulation^{29,30} through documentation of
135 similar accounts by multiple people and a member check with the community-based PR advisory
136 council for feedback on the results and interpretation.

137

138 **Results**

139 *Sample:* From the 129 people with TBI contacted for telephone screening, 57 persons with TBI,
140 21 family members, and 7 informants of those with TBI participated in the research. Reasons

141 people with TBI did not participate included not interested (20), no perceived deficits from TBI
142 (11), too low functioning (9), resides in nursing home and not interested (8), too busy (7), lives
143 too far away (6), no transportation (6), incarcerated (2), felon (2), and religious reason (1). The
144 21 family members were related to the participant with TBI: parent (13), spouse (7), sibling (1).
145 The 7 informants were 2 local poll workers and 5 employees at a local residential day care
146 program for people with TBI, for a total 85 participants enrolled. Of the 85 enrolled, 3 persons
147 with TBI and 3 family members provided demographic and voting participation data, but did not
148 provide an interview (resulting in interviews with 54 persons with TBI, 21 family members, and
149 7 informants for a total 82 interviews). Characteristics of the participants are summarized in
150 Table 1. Only 26% were employed at the time of the elections. Participants with TBI MMSE
151 scores were normal for the majority (70%), 23% mild, 7% moderate, and none severe cognitive
152 impairment. Family members all had MMSE scores within normal range except one with
153 moderate cognitive impairment).

154

155 [insert Table 1 about here]

156

157 Interviews were conducted within an average 41.3 days ($SD=77.78$) of the election date. Voting
158 participation for the persons with TBI and family members and their voting method are
159 summarized in Table 2.

160

161 [insert Table 2 about here]

162

163 *Study Findings:* Data analysis revealed four themes describe below. Tables 3, 4, 5, and 6
164 specify representative findings and quotes for each respective theme. The themes provide an
165 overarching conclusion: voting is a right and a responsibility of every citizen of the U.S. and the
166 question of whether or not a person with TBI is competent to vote is not a relevant question,
167 because voting is a right regardless of competence.

168 Theme 1: People with TBI have barriers to voting. Multiple barriers to voting were
169 identified, including cognitive impairment, time, transportation, physical, and social stigma.
170 Polling places are confusing and full of stimuli, people with TBI have difficulty remembering
171 and making choices, people with TBI may lack transportation, and poll workers interpersonally
172 stigmatize people with TBI. Some expressed uncertainties regarding capacity to vote.

173 Theme 2: The voting process can be improved for people with TBI. Participants suggest
174 ways the voting process can be improved for people with TBI, including: provide help
175 understanding candidates and their positions; provide help reading/understanding ballot/machine;
176 provide special area with more room/space; provide transportation and convenient location;
177 make people with disabilities comfortable voting; make process less confusing; help them make
178 a choice; make ballot clearer/easier to see.

179 Theme 3: Voting is the responsibility of members of society. Participants assert voting is
180 a way in which a person is a member of society, a symbol of belonging, freedom to take an
181 active role in one's future, and – bottom line – it is a right regardless of competence.

182 Theme 4: Voting is one way we have a voice in society. Voting represents a voice for
183 people with disabilities, a way to be heard, and a way to keep the need of people with TBI in the
184 forefront of the political process. It is possible, however, for the voice of a person with TBI to be
185 subsumed by their family members as they offer assistance in the voting process.

186 [insert Tables 3, 4, 5, and 6 about here]

187

188 **Discussion**

189 A PR approach was used to assess the voting experience of individuals with TBI through
190 semi-structured interviews and participant observation at the polls during the 2007 and 2008
191 elections in North Carolina. Four themes emerged. Although people with TBI experience
192 barriers, people with TBI may nonetheless overcome barriers because of belief in responsibility
193 and voice in society. While we note some differences in viewpoints between family members
194 and people with TBI, we found that, for the most part, family members were supportive of their
195 loved one with TBI voting and, as much as they could, provided assistance if the person with
196 TBI wanted to vote.

197 An interesting and unexpected finding was that overwhelmingly, both people with TBI
198 and family members express the view that cognitive capacity should not be a factor in voting.
199 Our participants' view on capacity provides data that overlaps with recommendations by the
200 American Bar Association, that any person who expresses a desire to vote, should be permitted
201 to vote.¹² However, occasionally family members do discourage those with TBIs from voting
202 such that they lose their voice.

203 Voting is more than a political voice; it is also a rehabilitation outcome. Self-expression
204 and membership in a larger group were particular drivers in this study with findings painting a
205 clear picture that for people with TBI voting represents freedom, active societal participation,
206 *and* having a voice.³¹ In the general population, better subjective health has been reported among
207 those who participate in voting and voluntary social activities than those who do not.³² From
208 these perspectives, voting is a key outcome for rehabilitation.³¹

209 Though two-thirds voted, there are barriers. We found people with TBI can require extra
210 resources (time, effort, transportation) to vote, and people with TBI may have challenges with
211 remembering to vote, preparing to vote, researching candidates, and arranging transportation to
212 the polls. Some people with TBI also note challenges navigating the polls and the ballot,
213 difficulty remembering who to vote for, stigmatization, and health issues. In 2014, the US
214 Department of Justice wrote that accommodations such as absentee ballot and curbside voting
215 should take the place of polling place voting in limited circumstances;³³ family/caregiver
216 assistance can help but may not fully overcome these barriers. Voting for many with TBI will
217 require self-advocacy (informing others what one needs to meet their goal), a skill that may be
218 compromised by the effects of the TBI.³⁴

219 Study participants did not mention by-mail absentee voting. By-mail voting may appear
220 to be the panacea to overcome polling place barriers for people with disability. A mail-in ballot,
221 which voters can complete at their convenience without any rush - might be among the best
222 approaches for people with disability. Do we even need to learn about the past barriers
223 encountered with polling places? With the convenience of by-mail voting, might everyone vote
224 by mail and polling places be obsolete in the future? There is mixed evidence about whether by-
225 mail voting (no excuse absentee voting) increases voter turnout.^{35,36} Evidence appears to indicate
226 reforms to increase voting by mail have made it easier for those with varied disabilities to
227 vote.^{1,37} In the 2018 US elections, 30.7% of voters with disabilities voted by mail, compared to
228 22.3% of voters without disabilities.² Yet, it is often suggested that providing increased absentee
229 voting (or curbside voting) is not adequate for those with disabilities.³³ Expanded by-mail voting
230 may especially increase the turnout of people with disabilities, as the voting gap between people
231 with and without disabilities was smaller in states with all-mail voting, and states with “no-

232 excuse” mail voting where voters do not have to specify a reason (such as disability) for
233 obtaining a mail ballot.³⁸ However, mail voting is not a panacea for voters with disabilities. In
234 the 2012 US elections, 13% of mail voters with disabilities encountered difficulties in filling out
235 or sending their mail ballot, and 11% required assistance, compared to only 2% and less than 1%
236 (respectively) of mail voters without disabilities.⁴ Although it sounds simple, mail-in voting can
237 pose many challenges to a person with TBI with impairment of vision, mobility, and cognition.
238 An audit in 2020 uncovered that more than 40 states do not have fully accessible webpages,
239 ballot applications, and absentee ballots.³⁹

240 In 2020, COVID-19 focused public attention on by-mail voting^{40,41} with national
241 discourse casting questions about the legitimacy of such mail-in voting, and voting preferences
242 divided along party lines.^{42,43} More than 65.6 million Americans voted by-mail 2020 US
243 Presidential election (65% of all votes), up from 33.6 million (24%) in 2016.^{44,45} While the
244 extent of mail voting increased, the basic process of by-mail voting has remained similar, so
245 difficulties in voting likely remain the same. With wide-spread distrust, it seems unlikely that
246 polling places will go away soon. People with disability, like those without disability, may prefer
247 to cast their vote in person to ensure their vote is counted or may need assistance that they do not
248 have at home. Or, they may not be able to navigate voting at home and need to vote in-person.
249 For many with physical disability, drive-up voting appears to be a solution. However, during the
250 2020 Presidential election, drive-up voting was contested in Harris County, Texas courts putting
251 approximately 127,000 votes at risk of not being counted and sudden closure of nine drive-up
252 sites.⁴⁶

253 *Implications:*

254 Strategies such as educating government officials, poll workers, election officials, brain
255 injury advocacy groups, and persons with TBI about TBI and voting are needed to address
256 difficulties with voting. This will rise in importance as TBI prevalence increases with the aging
257 US population.⁴⁷ Training materials and training expectations must be developed. People with
258 brain injury and their family/caregivers need information about voting. This can be done through
259 educational brochures, such as “Voting Tips for People Living With TBI”.^{48,49} Smith, et al.⁵⁰
260 pointed out that in a physicians’ mission to serve our patients, is the need to encourage our
261 patients to vote. To optimize the community integration of our patients, rehabilitation and other
262 healthcare providers can routinely discuss the importance of electoral participation, identify
263 obstacles, and explore strategies to overcome the obstacles.

264 *Directions for future research:* This study focuses on people with TBI who have voted,
265 but the findings also shed light on the especially low turnout of people with cognitive
266 impairments. Given the growing size of the population with TBI, a larger study is needed to
267 assess the generalizability of the findings. When the 2020 presidential election participation data
268 become available, analysis of participation method for those with and without disability will
269 provide important insights to add to the present study findings. It will also be important to study
270 the use of mail-in ballots among those with TBI.

271 *Strengths and Limitations:* The present study is one of the first to investigate the experience of
272 political participation among persons with disability, and the first study to investigate the
273 experience among persons with TBI. Learning about the experience directly from those affected
274 is a strength in this exploratory study of a complex topic. This study did not quantitatively
275 measure participation of impacts of impairments and function on participation. Although a
276 diverse array of participants was studied, our findings may not fully reflect the experiences of

277 others living with the effects of TBI and may not generalize to individuals with TBI who do not
278 receive inpatient rehabilitation. This was a convenience sample that included individuals with
279 moderate-severe TBI who in general had a high level of cognitive and physical function at the
280 time of study participation, and therefore, also may not represent individuals with TBI with more
281 severe disability.

282 Time has passed since these data about the 2007 and 2008 elections were collected,
283 though the lessons learned continue to provide insight into current aspects of the voting
284 experience. The disability gap in voter turnout has not narrowed since 2008 with the same factors
285 at work then likely at work now.² The gap between people with cognitive impairments and those
286 without disabilities was 18.4% in 2008, and 18.7% in 2016.^{2,4} That is, the disability gap in voter
287 turnout is remarkably stubborn over time, giving continued relevance to the study
288 findings. Research has shown that resources, recruitment, and psychological factors are
289 important in explaining the lower turnout of people with disabilities.^{4,51} The key resource factors
290 are income and education,¹ and the disability gaps in these factors have not changed in 2020, so
291 lower education and income levels are very likely to continue to contribute to lower voter turnout
292 among people with disabilities. The recruitment factor, whether anyone asked you to vote, was
293 likely lower during the pandemic due to social isolation of people with disabilities. The key
294 psychological factor is external political efficacy,⁵² reflecting whether one thinks the political
295 system is responsive to people like oneself. The difficulties of people with disabilities in the
296 pandemic may have contributed to lower feelings of efficacy.⁵² Taken together, despite the
297 substantial increase in voting by mail in 2020,^{44,45} the barriers to voting expressed by our
298 interviewees are likely to be relevant in 2020 and beyond.

299

300 **Conclusions**

301 This basic and crucial act of democratic participation represents freedom and voice. Barriers
302 continue to exist that threaten or limit the voice for people living with brain injury. Past research
303 on determinants of voting indicate that these barriers will continue to exist, supporting further
304 work to help ensure people living with TBI achieve this hallmark of societal participation.

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Appendix A: Voting interview questions

For the people with Traumatic Brain Injury:

1. Did you used to vote before your injury? Why/why not?
2. Did you vote in this election? Why did you vote/why not?
3. (if they voted) What was the experience of voting like for you?
4. (if they voted) Where there any barriers to you voting? If so, what were the barriers to voting?
5. (if they did not vote) What has gotten in the way of your voting?
6. Did you vote before your injury? If the answer is “no” follow up with:
7. What, for you, were the things that really got in the way of your voting *before* your injury
8. What, for you, were the things that really got in the way of your voting *after* your injury
9. When you talk about voting with others is your TBI an issue? Explain.
10. What does voting mean to you? What does it mean to vote? What does it mean to not vote?
11. What words would you use to describe the experience of voting in this country?
12. Fill in the blank: A person who votes is _____. A person who doesn't vote is _____.
Voting represents _____. The right to vote represents _____. The ability to vote represents _____.
13. How do you feel about people with disabilities voting? How do you feel about people with Traumatic Brain Injury voting?
14. Do you have any ideas on how the voting process could be improved for you? For people with Traumatic Brain Injury; For people with disabilities?
15. Do you feel that your thinking ability is affected by your injury? Do you feel competent to vote?
16. Do people think that your having TBI should affect your voting? Do people say anything to you--as a person with TBI--about voting? What do people think about you--as a person with TBI-- voting? Do you agree/disagree with them?

ASK THE FOLLOWING QUESTIONS IF THIS INFORMATION HAS NOT BEEN MENTIONED PREVIOUSLY

17. Does the fact that you have a TBI, or HAD TBI, have any bearing on whether or not you voted? In what way?
Does it have any bearing on your process of voting? On what it was like to vote? On how hard or easy it was for you to vote? On getting to the polls or navigating the polling place? On making a decision on who to vote for?
If you voted before your TBI, is the experience of voting now any different? In what way?
18. Do you feel you are a person living with a disability?
If they answer “no” At what point did you progress from having a TBI to being recovered? Can you describe *your* process?

If they answer “yes”. Ask them to explain what makes them feel disabled..

At what point, in your mind, did you progress from *not* being able to vote to being able to vote?

- Do you think that you could recognize these changes in someone else with TBI? Explain
19. How will you know when your TBI has progressed to the point where your TBI has changed to the point that you are no longer able to vote?

For the primary family member/ significant other:

1. Did you vote in this election? Why did you vote/why not?
2. (if they voted) What was the experience of voting like for you when you voted today?
3. (if it is not sure if they voted) Do you vote? Why/why not?
4. What does voting mean to you? What does it mean to vote? What does it mean to not vote?
5. What words would you use to describe the experience of voting in this country?
6. Fill in the blank: A person who votes is _____. A person who doesn't vote is _____. Voting represents _____. The right to vote represents _____. The ability to vote represents _____.
7. Do you feel [the person with Traumatic Brain Injury] is competent to vote? How do you feel about people with Traumatic Brain Injury voting? How do you feel about people with disabilities voting? How do you feel about people with cognitive impairment (such as Alzheimer's disease or dementia) voting?
8. Should he/she (the persons with the Traumatic Brain Injury) vote? Why/why not?
9. (if they voted) Where there any barriers to you voting? What do you see as the barriers to voting for you? Where there any barriers to voting for [the person with Traumatic Brain Injury]?
10. What do you see as the barriers to voting for people with Traumatic Brain Injury, in general? What do you see as the barriers to voting for people with disabilities, in general?
11. How will you know when your (spouses, significant others, person with TBI) TBI has progressed to the point where their TBI has changed to the point that they are no longer able to vote?
12. Do you have any ideas on how the voting process could be improved for [person]? For people with disabilities? For people with Traumatic Brain Injury?
13. Do you have any ideas on how the voting process could be improved for yourself?

What do people say to you about your voting? Do you agree/disagree with them?

14. What do people say to you about [your significant other ,spouse, the person with TBI] voting? Do you agree/disagree with them? Does the fact that (your significant other, spouse) have TBI, or HAD TBI, have any bearing on whether or not you voted? In what way?
15. In your opinion, does their TBI have any bearing on his/her process of voting? On what it was like to vote? On how hard or easy it was for him/her to vote? On him/her getting to the polls or navigating the polling place? On making a decision on who to vote for?
16. Do you consider yourself to have any deficits/difficulties/disabilities that might affect your voting experience?

Table 1: Participant characteristics

	Participants with TBI n = 57		Family Members n = 28	
	Mean	SD	Mean	SD
Age at Injury	41.2	25.5	52.1	2.1
	N	%	N	%
Sex				
Males	41	71.9%	9	32.1%
Females	16	28.1%	19	67.9%
Race/Ethnicity				
White	37	64.9%	22	78.6%
Black	18	31.6%	5	17.9%
Other	2	3.2%	1	3.6%
Hispanic	2	3.2%	0	0%
Education Level				
Less than high school	10	17.5%	1	3.6%
High school diploma or GED	15	26.3%	5	17.9%
Associate or Bachelor's Degree	28	49.1%	15	53.6%
Graduate Degree	4	7.0%	6	21.4%
(Missing)	0		1	3.6%
Employed				
Employed	15	26.3%	17	60.71%
Not Employed/retired/disability	38	66.7%	8	21.1%
(Missing)	4	7.0%	3	10.7%
MMSE score				
Normal cognition	40	70.2%	27	96.4%
Mild impairment	13	22.8%	0	0%
Moderate impairment	4	7.0%	1	3.6%
Severe impairment	0	0%	0	0%
Cause of Injury				
Vehicular	26	45.6%		
Violence	6	10.5%		
Falls	4	7.0%		
Other	4	7.0%		
(Missing)	16	28.1%		

Abbreviations: SD: Standard Deviation; MMSE = Mini-mental State Examination; GED: General Education Development

Table 2: Voting Participation among the Sample of Registered Voters

	November 2007	May 2008	November 2008
Participants with TBI	N = 19	N = 19	N = 19
Did not vote	9 (47.4%)	9 (47.4%)	3 (15.8%)
Voted	10 (52.6%)	10 (52.6%)	16 (84.2%)
-- Voted by absentee ballot	0	0	2
-- Voted at polling station	10	10	14
Family Members	N = 12	N = 4	N = 12
Did not vote	4 (33.3%)	2 (50.0%)	1 (8.3%)
Voted	8 (66.7%)	2 (50.0%)	11 (91.7%)
-- Voted by absentee ballot	2	0	2
-- Voted at polling station	6	2	9

Table 3: Representative findings and quotes for theme 1

Theme 1. People with TBI have barriers to voting.	
Finding	Example Quotes
Cognitive barriers	<p>“I think it would probably just take him longer reading and the memory. I guess like the memory thing.” [FAMILY]</p> <p>“The _____ area [TBI survivors] group had a meeting about voting and I had the opportunity to listen to a lot of the survivors talk about how difficult it is for them, number one getting there, finding the polling place, getting there, the confusion of all of the people, the noise, the lights, the talking. The actual physical operation of the voting machine. Now, ours is a touch screen. I don’t know what, ... I don’t know if that’s a county type thing or not but they were talking about how they didn’t know how to use the touch screen. The abundance of choices they have to make in a very short amount of time – because they’re going to want to read everything. The pressure to hurry up and get out of there so the next person can use the machine.” [FAMILY]</p> <p>“And then barriers as far as maybe an impairment as far as sight or sound, not being able to hear. They may not be able to see the words, like, on the screen. Even though it’s a touch screen they may not be able to fully move their arm or whatever. Many of them have other injuries related to the brain injury that all occurred at the same time so physically and mentally they may not be able to read through the instructions or completely understand it so they might need someone else to read it. So that might be a barrier if there’s not people available to do that.”</p> <p>“Last time I went to the polls it was a circus for me to figure out how to vote, not the mechanics of it, but just the best thing for me to vote for.” [PERSON WITH TBI]</p>
Time and transportation barriers	<p>“[A barrier to my voting is] getting there, how far it would be, what time of day, because it’s only for one day. I have to figure out the most available time for me to go and I have to count on the lines and how long it would take me to get to work after that.” [PERSON WITH TBI]</p> <p>“Driving is one of them. I can’t drive anymore.” [PERSON WITH TBI]</p> <p>“Well, as far as probably transportation, many of them can’t drive so they have to wait and get a ride from somebody else or get a taxi or whatever.” [FAMILY]</p>
Social stigma barriers	<p>“They look at me and they think that I am mentally retarded and spaced out and that don’t count. I am so tired of that. And I have to keep reminding them-look, I’m not deaf and I’m not blind and I’m not retarded.” [PERSON WITH TBI]</p> <p>“What we encountered at the first voting place, you know, was so offensive to me and I realized that I need to call the voting election place because if they</p>

	<p>were that abrasive and that, I mean if I did not have [someone] with me I would have just gone home and probably cried and said, ‘Well maybe, God, I’m not supposed to vote’ because that man was just so abrasive.” [PERSON WITH TBI]</p>
<p>Barriers due to lack of confidence and second thoughts</p>	<p>“One of the problems, I think, for someone with a head injury if you vote, like I voted, but if you thought you understood everything, you did the best you could, but then maybe you don’t like what’s happening or you voted for somebody and now things are bad, then it makes you discouraged to vote the next time because it makes you think, oh, I’m not understanding what’s happening. And I know there’s a part of me that knows that whoever you vote for stuff doesn’t always turn out like what you would think but that is something with head injury that people if they vote and then it was a bad choice.” [PERSON WITH TBI]</p>
<p>Barriers due to uncertainty of family / caregivers whether or not person with brain injury has capacity to vote</p>	<p>“For someone like my son I just consider it, you know we prepare him ahead of time, we make sure he understands what he is voting for. And I’m just going to use him as an example because ability does, is everything for him, with the brain injury. There is one thing that, you know I was wish-washy about, you know, should we let him vote? Shouldn’t we let him vote? People across the street from us have two, umm, daughters from birth that were injured and so they are mentally handicapped and they vote every time too and they understand what they are voting for also. And umm, so his ability to vote is just umm, it’s precious. And that is how I look at it.” [FAMILY]</p> <p>“I know that my son there was no way in the world that he would completely understand the proposals. For example he has some strong feelings about some social issues so candidates are easier because one party basically represents one group of social issues, in general, and another represents another. But if he didn’t have somebody to help him understand those proposals, the way they are written, he would be in deep trouble. That would concern me if no one explained to brain injured people well enough so that they understood what they were voting for.” [FAMILY]</p> <p>“I think that his attention span is very short. And I think that because he was in his coma for so long that he has kind of missed out on what’s been going on in the world because a lot of things have changed real quickly. And I think that he needs to personally recover with the little things in his life and not worry so much about what higher up officials say and do because if he cannot speak, and he can barely say a couple of words, then I don’t think he’ll be able to speak his opinion. I don’t think he’s going to be comfortable with what he said and I just don’t think that he is competent enough right now to do that.” [FAMILY]</p> <p>“Seeing that he was probably, because of the state that he was in, I would have to do a lot of discussion with him just to determine whether he really knows what is going on. I would have to make the determination. If I felt he did not know what was going on, I don’t think I would let him vote, to be honest with you. There’s no sense in letting someone vote who doesn’t know what’s going</p>

	<p>on to really give the election.” [FAMILY]</p> <p>“She just doesn’t. She doesn’t understand any abstract concepts at all. She doesn’t have the ability to discern ... I don’t even have the ability to discern who’s telling the truth, how is she going to do that? She doesn’t read anything but teen magazines and that kind of thing – she doesn’t read the paper.” [FAMILY]</p>
<p>[Response to] barriers due to perception of individuals with brain injury that they should vote</p>	<p>“We still have a mind. We can still think. We can still decide. We’re just considered to be on a different level because of that injury. It doesn’t make us stupid. It just makes us think. We think, I think a lot deeper because I don’t have other problems so I think a lot deeper.” [PERSON WITH TBI]</p>

Table 4: Representative findings and quotes for theme 2.

Theme 2. The voting process can be improved for people with TBI.	
Finding	Example Quotes
A person with TBI has to take intentional action to be informed	<p>“I voted straight [ticket] when I did vote in the main election for the President, I voted straight down. But, yeah, I can see where I could have had a mental barrier because I would have had to make decisions [had I not voted straight ticket].” [PERSON WITH TBI]</p> <p>“I went in there with a piece of paper of who I wanted to vote for. I went to the list to find people and those were who I voted for. I did research by like reading the paper and stuff. I kept up on it.” [PERSON WITH TBI]</p>
A person with TBI needs support from their families in order to vote	<p>“I want him to feel safe and confident that he’s going in there and is really comfortable with what he’s going to do. I’ll provide him with whatever I can to help him get his research or his background.” [FAMILY]</p> <p>“I try to let him vote in his own way, his own feelings. . . . “we discuss the issues and the candidates. He knows how I feel. But we try to let him decide for himself what he wants to do. I don’t go in there and pull the lever for him.” [FAMILY]</p>
A person with TBI needs special support in order to vote	<p>[Help for people with TBI to vote would include] prompting them that today is Election Day, can you get out? Can you go to the poll? Do you need help? Providing assistance. Those are things I think, should be afforded people who have disabilities. Assistance, transportation, prompts, maybe an absentee ballot, you know, some means should always be available to people who are capable of voting.” [FAMILY]</p> <p>“Now I’m not really familiar with what the process is currently. I wasn’t here back in November when they voted. But I would think if there could be a facility specifically for people with disabilities, if transportation was provided and people were there to help them navigate that process as far as reading and whatever physical impairments they may have helping them to make their choices.” [FAMILY]</p> <p>At the polls, yes. If the polls were brought down where they could sit, if they were open . . . this room, if it were more of an open space. If they felt like they were given more time. If they felt like there wasn’t a line full of people standing behind them. If you feel like you are not being pushed. And you said, I didn’t know this, but you said that you can even take somebody in there to help you. If they had someone, just sometimes knowing that someone else is there to sit with you – “If you need any kind of help, I’m here” – sometimes that’s enough, just to do that.” [FAMILY]</p>

Table 5: Representative findings and quotes for theme 3.

Theme 3. Voting is the responsibility, right, and privilege to be members of society.	
Finding	Example Quotes
Voting as being a member of our society	“I love to vote because I’m a U.S. citizen and I have a right to vote and I just think that you should vote if you are a citizen of the United States. You should be voting – it’s your privilege, it’s your right.” [PERSON WITH TBI]
Voting as a symbol of belonging	<p>“[Voting is] showing that you’re ... part of the political system.” [PERSON WITH TBI]</p> <p>“[Voting] makes her feel like she’s done something special. Yeah, yeah. She always gets the little tag that says “I voted.” She likes doing it because she feels like she’s done something to be involved.” [FAMILY]</p>
Voting represents the freedom to make choices and decisions, and take an active role in one’s future	“It’s your chance to feel like you have some sort of power and control in a small part of the way the nation is going to go.” [PERSON WITH TBI]
Voting is a right regardless of competence	<p>“If they are able to comprehend and do everything, you’re still a person, you’re still a human. If you’re American and you’re human you can do it.” [FAMILY]</p> <p>“They have disabilities and limitations, but they are also citizens of the United States and they have that right also.” [FAMILY]</p> <p>“Because . . . you don’t want them to feel left out just because of their ability or because their brains don’t function like other people’s. They have a right to vote too even though they have a disability.” [FAMILY]</p> <p>“If they say they want to do it they should be able to do it regardless of what their cognitive impairment is or what their level of competency is. If they say they want to do it, they should be able to do it.” [FAMILY]</p> <p>“His heart beats just like ours, so if he wants to (vote) and feels comfortable with it, then whether his answers are right or wrong then he should (vote).” [FAMILY]</p> <p>“The only reason that you shouldn’t vote is if you’re dead.” [PERSON WITH TBI]</p>

Table 6: Representative findings and quotes for theme 4.

Theme 4. Voting is one way we have a voice in society.	
Finding	Example Quotes
A voice for people with disabilities	<p>“I voted because I feel like if I don’t vote then I was not able to express myself. I have still given my opinion, whether it changes the election or not.” [PERSON WITH TBI]</p> <p>“The ability to vote represents a privilege that I need to do because I have had an incredible recovery. If you would have seen me twenty years ago, I couldn’t have voted that year. I was so badly injured, my brain was so ... it felt like mud – I couldn’t think right, I couldn’t remember anything. I want to vote for all the people with disabilities that are not able to get out there and vote due to the severity of their brain injury or due to their mobility problems ... you know, I was set after my accident. When my parents arrived at the hospital, the surgeons came out and spoke to them very bluntly and said your daughter will be a vegetable if she makes it through this first night, your daughter will be a vegetable for the rest of her life. And I am so grateful because I know, after working, going in to the professional field of working with people with brain injuries I know a lot of people who didn’t ever come out of their coma, who were never able to enter back into normal life. I am probably in the top three percent ... three to five percent of people who have been able to have the kind of recovery that I have, so I want to represent those people that now cannot vote.” [PERSON WITH TBI]</p>
A way to be heard	<p>“Everybody gets to voice their choices.” [PERSON WITH TBI]</p> <p>“It’s a voice that I have in the United States. . . . And it’s a way that I can be heard. And it’s an action that it doesn’t cost me anything and it’s a plus in my life to say that I was responsible for that or I tried for that, you know, to let my vote be counted. It’s my right.” [PERSON WITH TBI]</p>
A way to keep their needs in the forefront of the political process	<p>“Well I certainly think that they should vote and it is part of their right as members of our society. And they have particular viewpoints which need to be registered because they go through experiences that are somewhat unique from most people. And if we who have been through those experiences don’t have our voices heard then chances are that we will have less representation for our specific interests which are a little different because of what we have been through.” [FAMILY]</p> <p>“I feel that maybe we who had TBIs would be in a minority and we may not demand the press coverage that another issue may. But yes, I think it’s important that the candidate be cognizant of that for the other people.” [PERSON WITH TBI]</p>
Cognitive limitations may cause people with	<p>“We have gone and we have voted, but she usually votes the way I vote.” [FAMILY]</p>

TBI to lose their voice	
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