

# Willingness to Favor Aggressive Care and Live with Disability Following Severe Traumatic Brain Injury: A Survey of Healthy Young Adults in Hawai'i

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## Abstract

*Traumatic brain injury (TBI) is a major public health problem that significantly impacts young adults. Since severe TBI patients lack decision-making capacity, the providers and patient surrogates are often faced with the challenging task of deciding whether to continue with aggressive life-prolonging care or to transition to comfort-focused care with an expected outcome of natural death. The assumption is often made that aggressive care is appropriate for young patients who suffer severe TBI despite the high likelihood of a poor outcome. However, the young community's attitude towards goals of care after severe TBI has not been studied. A questionnaire-based survey study on young healthy adults was conducted to assess their attitude towards aggressive care after a hypothetical case of severe TBI. Logistic regression analysis was performed to determine the factors associated with the decision to favor aggressive care. Among a total of 120 community-dwelling young adults (mean age: 19±1 years) who were surveyed, 79 (66%) were willing to live with severe motor disability, 78 (65%) were willing to live with expressive aphasia, and 53 (44%) were willing to live with receptive aphasia. Despite being presented with a high likelihood of long-term moderately severe-to-severe disability, 65 of the 115 respondents (57%) favored aggressive care. A willingness to live with receptive aphasia was the only independent factor that predicted aggressive care (OR 2.50, 95% CI: 1.15 to 5.46). Even among the young adults, preference of care was divided between aggressive and conservative approaches when presented with a hypothetical case of severe TBI.*

## Keywords

*Quality of life; traumatic brain injury; ethics; end-of-life care*

## Introduction

Traumatic brain injury (TBI) is a major public health problem that significantly impacts young adults, with an estimated incidence of 1.5 million total cases per year in the United States.<sup>1</sup> Compared to mild or moderate TBI, severe TBI is associated with worse outcomes.<sup>2</sup> In Hawai'i, approximately 36 cases of severe TBI are admitted to the state-designated trauma center annually.<sup>3</sup> Although the majority of patients with severe TBI may survive after aggressive neurosurgical and neurocritical care management, only about 25 percent of them achieve long-term functional independence.<sup>2,4,5</sup> Furthermore, 5 to 15 percent of patients with severe TBI are discharged in a vegetative state;<sup>4,5</sup> only about half of these persons eventually regain consciousness but with chronic severe disability.<sup>6</sup>

In a neurocritical care setting where patients are unable to make important end-of-life decisions due to their neurological injuries, the families and/or surrogate decision-makers are often faced with the challenging task of making a major decision in the patient's goals of care: whether to continue with aggressive life-prolonging care in the intensive care unit or to transition to comfort-focused care with an expected outcome of natural death. The process of coming to the final decision in

this ethically challenging situation often involves utilizing the "substituted judgment" standard and is based on the family and/or surrogate's understanding of the patient's previously stated wishes and known values.

When deciding to proceed with a life-saving treatment in a young patient despite the low likelihood of a favorable outcome, families and providers often presume that aggressive care is justified.<sup>7</sup> Frequently, the assumption is made that every young person would want to survive even with severe cognitive and/or physical disability. In most circumstances, young adults have not had an opportunity to express their wishes in the fairly unlikely circumstance of a severe brain injury resulting in a loss of decision-making capacity at a young age, thus leaving no information for the surrogate decision-makers to base their substituted decision-making. Parents, who often serve as the surrogate decision-maker, often view their young adult child as a vulnerable 'minor' who needs protection. As a result, they often make a paternalistic decision rather than acting upon the values of the patient (principle of autonomy).<sup>8</sup> Although the patient's values and wishes must be individualized, improving our general understanding of the young community's perception and attitude towards goals of care after severe TBI may assist the providers and families with the complex decision-making process in these challenging situations.

## Methods

An approval from the University of Hawai'i Institutional Review Board was obtained to conduct a cross-sectional, questionnaire-based survey study by having young healthy adults (age ≥ 18) in the Honolulu County take an anonymous paper survey. The primary objective of this study was to assess the proportion of respondents who favored aggressive care after severe TBI. The secondary objective was to assess the perception of TBI disability and to identify the factors that would predict the young adults' decision to favor aggressive care after a hypothetical case of severe TBI. To simulate a realistic clinical decision-making dilemma, the respondent's willingness to receive aggressive care despite a high likelihood of moderately severe-to-severe long-term neurological disability after the treatment was specifically assessed. The highest degree of neurological disability they would be "willing to live with" based upon the descriptions from the modified Rankin Scale (mRS) (Table 1) was also assessed. The recruitment and data collection took place at public spaces, but the surveyor targeted areas with a high concentration of young adults such as high school athletic gyms, football fields, a local shopping mall, and private social

Table 1. Primary Outcome Questions
<p>1) What is the most severe disability level you would be willing to live with?</p> <p>0: No symptoms at all.  1: No significant disability despite symptoms; able to carry out all usual duties/activities.  2: Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance.  3: Moderate disability; requiring some help, but able to walk without assistance.  4: Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance.  5: Severe disability; bedridden, incontinent and requiring constant nursing care and attention.</p>
<p>2) If you have a severe traumatic brain injury that will most likely result in moderately severe or severe permanent disability (see above definitions) or death no matter what type of treatment you get, would you choose treatment that is:</p> <p><b>Aggressive:</b> involving temporary removal of your skull to relieve high pressure from brain swelling, removing a blood clot within the skull that may be causing damage to your brain, and/or prolonged care in the intensive care unit in the hospital. This will increase your chance of survival, but you would have moderately severe or severe disability.</p> <p><b>Conservative and noninvasive:</b> This will likely decrease your chance of survival. If you survive, you would have moderately severe or severe disability. You will likely pass away comfortably in a natural way.</p>

events. The participants were screened to be “young adults” based on the surveyor’s subjective assessment of their physical appearance. Participants were included in the survey after confirming that they met the minimum age requirement (age  $\geq 18$ ). Besides the surveyor’s subjective assessment of their “young adult” appearance, there was no upper age limit for enrollment. No incentive was provided for survey completion. Convenience sampling methodology was used in this study. Due to the exploratory nature of the study, power analysis was not performed. Waiver of consent was obtained from the Institutional Review Board to conduct this survey study since agreeing to take an anonymous paper survey was considered to be adequate consent.

### Data Collection and Measures

The study personnel directly collected the self-administered paper surveys that were completed at the time of recruitment. Collected data included personal and demographic characteristics including the respondent’s age, sex, race, education level, annual income, occupation, marital status, family status, insurance status, whether they had previously discussed with anyone the severity of disability they are willing to live with, and whether they knew someone who previously had a TBI, stroke, or other brain injury. Race was categorized as white, Asian, Native Hawaiian and other Pacific Islander (NHOPI), or “other” race. Since mixed racial background is relatively common in Hawai’i, race was defined as the racial background that the respondent most closely associates with and was based on self-identification. The primary outcome measure was to determine the young community’s willingness to receive aggressive care. Respondents were presented with a hypothetical case of severe TBI with clinical features that would lead most healthcare providers to portray a poor neurological outcome if this were a “real life” setting (Table 1). Aggressive care was described to portray decompressive hemicraniectomy and prolonged intensive care treatment. Conservative care was defined as “noninvasive treatment.” The secondary outcome measures

included the young community’s attitude towards the highest acceptable neurological disability that they would be “willing to live with,” according to the mRS description. In addition to using the mRS, respondents were asked about specific language and motor disabilities that they would be “willing to live with.” Expressive aphasia was described as “difficulty speaking”, and receptive aphasia was described as “difficulty comprehending.”

### Statistical Analysis

Data analysis was conducted through commercially available statistical software (SPSS 22.0, IBM Chicago, IL). Descriptive summary statistics were calculated for all variables. After dichotomous grouping based upon whether or not aggressive care was favored, t-test and chi-square testing were performed, based on the variable types, to compare variables between the two groups. Multivariable logistic regression models were performed with forward stepwise inclusion of all variables with  $P < .10$  in the univariate analysis (female sex, willingness to live with expressive aphasia, and willingness to live with receptive aphasia), to determine the factors associated with favoring aggressive care after severe TBI. Odds ratio (OR) and 95% confidence interval (CI) were calculated from the beta coefficients and their standard errors. Data are presented as means  $\pm$  SD, and levels of  $P < .05$  are considered statistically significant.

### Results

A total of 120 young adults in the community (mean age:  $19 \pm 1$  years, female 37%) were approached, recruited and surveyed. The response rate was 100%. The demographic and survey results of all respondents are shown in Tables 2 and 3. The racial, ethnic distribution consisted of a large proportion of Asian (37%) and NHOPI (37%) respondents compared to whites (20%). Overall, 79 (66%) respondents were willing to live with a severe motor disability, 78 (65%) respondents were willing to live with expressive aphasia, and 53 (44%) respondents were willing to live with receptive aphasia. The highest acceptable

	n ± SD [n (%)]
Age, years	19 ± 1
Female	44 (37)
Race/Ethnicity*	
White	24 (20)
Asian	44 (37)
Native Hawaiian and Other Pacific Islanders	44 (37)
Other	7 (6)
Education level	
High School	42 (35)
College	77 (64)
Graduate School	0 (0)
Other	1 (1)
Annual income	
<\$15,000	115 (96)
\$15-40,000	1 (1)
\$40-80,000	2 (2)
>\$80,000	2 (2)
Full time student	108 (90)
Married	1 (1)
Have children	2 (2)
Have health insurance	111 (93)
Know someone who had traumatic brain injury (TBI)	42 (35)
Have a family member who had a TBI, stroke or other brain injury	54 (45)
Previously discussed the level of disability that is worth living with parents, guardian, spouse or children	21 (18)

\*One respondent did not report race.

	n (%)	95% CI
Willing to live with a severe motor disability	79 (66)	57 – 74%
Willing to live with expressive aphasia	78 (65)	56 – 74%
Willing to live with receptive aphasia	53 (44)	35 – 54%
Favoring aggressive care after severe traumatic brain injury*	65 (57)	47 – 66%
Most severe mRS score willing to live with:		
0	12 (10)	5 – 15%
1	15 (13)	6 – 19%
2	17 (14)	8 – 20%
3	44 (37)	28 – 45%
4	23 (19)	12 – 26%
5	9 (7)	3 – 12%

\*Only 115 respondents answered this question.

modified on the Rankin Scale (0–5) participants “willing to live with” chose: 0 (10%), 1 (13%), 2 (14%), 3 (37%), 4 (19%), 5 (7%). Only 21 (18%) respondents reported having had a discussion with their families about the level of disability they were willing to live with.

Among the 120 respondents, five did not answer the question about the intensity of care they hypothetically desired (aggressive vs. conservative) during the survey. Among the 115 respondents who answered this question, 65 (57%) favored aggressive care despite the high chance of long-term moderately severe-to-severe disability. Univariate analyses showed that those who favored aggressive care were more likely to be willing to live with receptive aphasia than those who favored conservative care (55% vs 33%,  $P = .02$ ). There were no significant differences in the demographics or the highest acceptable disability between the two groups (Table 4). In the multivariable analyses using a stepwise logistic regression model, a willingness to live with receptive aphasia was the only independent factor associated the decision to favor aggressive care (OR 2.50, 95% CI: 1.15 to 5.46,  $P = .02$ ).

## Discussion

More than half of the young adults in the community in this study responded in favor of wanting aggressive neurosurgical and neurocritical care after hypothetically experiencing severe TBI, even when given the high probability of a profoundly disabling outcome. Similar to a prior study that surveyed young adults with a hypothetical case of malignant middle cerebral artery (MCA) stroke syndrome,<sup>9</sup> most young adults (73-92%) in this study stated they would not want to live with a moderately severe-to-severe disability (mRS 4-5). Despite this unwillingness to live with a moderately severe-to-severe disability, when presented with a clinical scenario with high likelihood of undesirable outcome, many respondents still favored aggressive care. This may reflect the positive outlook, with hopes of “beating the odds,” that many individuals naturally exhibit when suffering from a devastating illness.<sup>10</sup> In fact, the highest acceptable neurological disability that they would be “willing to live with,” based on the mRS description, did not correlate with the decision to favor aggressive care, which was consistent with a prior study.<sup>9</sup> The only independent factor that predicted the response in favor of aggressive care was a

Table 4. Comparison of respondents' characteristics			
	Aggressive n ± SD n (%)	Conservative n ± SD n (%)	P
No. of patients	65	50	
Age, years	19 ± 1	19 ± 1	0.72
Female	28 (43)	14 (28)	0.10
Race/Ethnicity*			0.34
White	14 (21)	9 (18)	
Asian	27 (42)	14 (29)	
Native Hawaiian and Other Pacific Islanders	20 (31)	23 (47)	
Other	4 (6)	3 (6)	
Education level			0.19
High School	27 (41)	14 (28)	
College	38 (59)	35 (70)	
Graduate School	0 (0)	0 (0)	
Other	0 (0)	1 (2)	
Annual income			0.41
<\$15,000	62 (95)	48 (96)	
\$15-40,000	0 (0)	1 (2)	
\$40-80,000	2 (3)	0 (0)	
>\$80,000	1 (2)	1 (2)	
Full time student	59 (91)	46 (92)	0.68
Married	0 (0)	1 (2)	0.25
Have children	1 (2)	1 (2)	0.85
Have health insurance	60 (92)	46 (92)	0.72
Know someone who had TBI	22 (34)	17 (34)	0.97
Have a family member who had a TBI, stroke or other brain injury	30 (46)	22 (44)	0.76
Previously discussed the level of disability that is worth living with parents, guardian, spouse or children	12 (18)	6 (12)	0.34
Willing to live with a severe motor disability	46 (71)	30 (60)	0.23
Willing to live with expressive aphasia	47 (72)	28 (56)	0.07
<b>Willing to live with receptive aphasia</b>	<b>36 (55)</b>	<b>16 (33)</b>	<b>0.02</b>
Most severe mRS score willing to live with:			0.51
0	7 (11)	5 (10)	
1	7 (11)	7 (14)	
2	6 (9)	10 (20)	
3	24 (37)	17 (34)	
4	16 (25)	7 (14)	
5	5 (7)	4 (8)	

NHOPI, Native Hawaiians and other Pacific Islanders; TBI, traumatic brain injury; mRS, modified Rankin Scale. Data are n (%) or mean ± SD. Percents may not total to 100% due to rounding. \*One respondent did not report race.

willingness to live with receptive aphasia. Perhaps, these results are suggestive of an aversion to poor cognitive outcomes, but a relative willingness to live with acceptable physical disability among young adults.

This study suggests that surrogate decision-makers may not be able to extrapolate a young adult's willingness to pursue aggressive treatment based on the patient's perception of physical disability. Perhaps the discussion involved in attempting to determine the intensity of care should focus on the most likely cognitive outcome after severe TBI such as the possibility of receptive aphasia or minimally conscious state. However, explicit discussion of the individual's unique values and previously stated wishes is still recommended to make the most accurate substituted decisions, since every individual will likely have a unique perspective on this topic. This study shows that only 18% of the respondents have previously discussed with their families the level of disability that they were "willing to live with," which highlights the importance of practitioner-initiated early discussions about the desired quality of life and goals of care in a hypothetical emergent medical condition even among the young adult population.

This study has several limitations. Although everyone who was approached by the study personnel agreed to participate in the survey, it was difficult to assess the true non-response rates in the public survey setting since some people may have avoided being approached by the study personnel altogether. Thus the impact of potential participation bias remains uncertain. The survey responses to a hypothetical situation may differ based on prior experience with a real disabling illness.<sup>11</sup> The level of understanding of these participants, and their abilities to make an informed decision remains uncertain since the survey did not give them the opportunity to ask specific medical questions. Therefore, the results of this study may not reflect the "real life" decision-making process, as it occurs within the complex context of acute-onset life-threatening illness, since the real life setting would involve extensive medical discussion with the expert physicians and support staff. Pre-specified power calculations were not made, and thus the negative results do not prove a lack of association. The small sample size limits the conclusions drawn from this study to preliminary observations. Finally, this study was conducted in a predominantly Asian and NHOPI community in the Honolulu County area with high proportion of educated, unmarried young students (age range: 18-22) with health insurance; thus the results of this study may not be generalizable to other populations with different age strata and socioeconomic backgrounds.

## Conclusion

This study shows that even among young adults, preference of care was divided between aggressive and conservative approach when presented with a hypothetical case of severe TBI. The respondents' decisions to favor aggressive care were related to their willingness to live with receptive aphasia but were not associated with their level of expected physical disability. Further studies in larger populations and in healthcare settings are needed to gain a better understanding of the "real life" factors impacting young adults' decisions regarding aggressive care after severe TBI.

## Disclosure

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## Conflict of interest

None of the authors report a conflict of interest.

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