

Gender and Race Based Discrimination in Disability Care: Quantitative and Qualitative Approaches

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When it comes to disability care, the Systemic, Therapeutic, Assessment, Resources, and Treatment program (otherwise known as START) is an ongoing effort to support patients with intellectual/developmental disabilities (known as IDD) or patients with various mental health needs (Center for START Services). As disability care is still lacking in many aspects and medical staff are frequently subject to biases that affect their patients' quality of care, our research aims to examine the demographic groups in the START program who receive the lowest quality of care and the general areas of care that patients need addressed. To carry out our analysis, we used both the START demographic data and the Family Experiences with Severe Mental Illness Scale (FEIS) response survey, which collected quantitative and qualitative family responses regarding their loved one's quality of life under the START program. After splitting the master data into four subsets determined by gender (Male/Female) and race (White/Nonwhite), we calculated the general level of satisfaction for each subset and conducted topic modeling on family advice. Among this dataset, we found that the highest levels of in-patient crisis care are among nonwhite female patients, and that families of nonwhite patients reported lower levels of "very satisfied" than families of white patients. Additionally, our findings showed that families were primarily concerned with interpersonal relations, staff response to services, and access to resources regarding the patients' care.

IDD | Discrimination | Demographics | Family Feedback | Disability

Introduction

The START (Systemic, Therapeutic, Assessment, Resources, and Treatment) model can be applied to a variety of programs that aim to provide crisis intervention for individuals with intellectual/developmental disabilities. START is a community based model that provides a myriad of services such as on-call crisis support, psychiatric consultation, and therapy with the goal of improving the lives of those with IDD. Although programs such as these offer many kinds of services and support for these individuals, there is no ignoring the role that gender and racial discrimination/bias play in care for disabled individuals.

Related Work. Existing literature already points to race-based and gender-based disparities in the care of disabled individuals. One study used quantitative data from the 2006 National Health Interview Survey (NHIS), and results showed that women with disabilities had less access to

Significance Statement

Discrimination in the healthcare sector is frequent but overlooked, especially when dealing with the degree of life of disabled individuals. Thus, it is imperative that the standards of care for disabled patients be quantified to some degree to accurately identify the demographics in need of the most assistance. Furthermore, pinpointing the exact areas of need for these patients is also crucial to improving their quality of care, as medical staff must know where and how to adjust their current methods to compensate for areas where care is lacking.

12 healthcare than both women without disabilities and men with disabilities; in the study, “those
13 who were disabled are 2.26 to 3.78 times more likely to not have access to health care, and women
14 were 1.26 times more likely to not have access to health care.” The study concluded that disability
15 and gender are both predictive of a lack of access to healthcare. We hoped to expand this work by
16 investigating disparities not only in relation to access to healthcare, but in the quality of healthcare
17 accessed, asking whether the demographic factors that influenced whether an individual was likely
18 to receive healthcare also played a role in the quality of that care and ultimately, their satisfaction
19 with the care they received.

20 Similarly, a 2011 report from the Office of Minority Health of the U.S. Department of Health and
21 Human Services (HHS) concluded, “By every measure, persons with disabilities disproportionately
22 and inequitably experience morbidity and mortality associated with unmet health care needs in
23 every sphere. Minorities with disabilities are doubly burdened by their minority status.” This
24 report highlights existing racial prejudice that disabled minority individuals face when seeking out
25 healthcare. The concept of the “double burden” was especially important for our work, since it
26 specifically spoke to the compounding of demographic factors that further limited access to quality
27 healthcare. Few intersectional studies exploring both the effects of gender and race on disabled
28 individuals’ access to quality care existed, but this sparsity was part of what informed our approach
29 to our analysis, as we saw an opportunity to address an existing gap of intersectionality in disability
30 literature.

31 Certain studies also focus on the overrepresentation of minorities in psychiatric inpatient care; a
32 2009 study specifically focused on the documented overrepresentation of Black patients relative to
33 white patients in psychiatric inpatient treatment facilities. The psychological toll this inflicts on
34 minorities is evident; “inpatient psychiatric treatment is particularly stigmatizing to patients and
35 may fuel mistrust of the health system among Blacks,” (Snowden et al.) This knowledge proved
36 relevant to our analysis of fields in the dataset that recorded incidence of inpatient psychiatric care
37 across demographics.

38 Likewise, existing qualitative literature considers the histories and modern day effects of medical
39 racism and ableism in healthcare. Suite et al. discuss how histories of medical racism entrenched in the
40 legacy of chattel slavery and white supremacy, including pseudoscientific racial stereotyping, patterns
41 of misdiagnosis of mental health conditions, and unethical and illegal medical experimentation have
42 created distrust in the American mental health system amongst people of color, particularly for
43 Black Americans (879-883). In many ways, medical racism continues throughout the present. Suite
44 et al. explain that internationally, racial minorities are more likely to be diagnosed with serious
45 mental disorders and less likely to be diagnosed with less serious mental disorders, as denoted by the
46 “overdiagnosis of schizophrenia and underdiagnosis of affective disorders among African Americans,
47 Afro-Caribbeans, and Latinas/os, compared with the overall prevalence of these disorders in the
48 psychiatric inpatient population, which corroborate the findings of Snowden et al. (881).

49 Iezzoni and Long-Bellil note the necessity of physician-patient interactions in order for disabled
50 individuals to access appropriate healthcare services and observe the distinct lack of disability-related
51 training amongst healthcare professionals (136-137). They call on the need for “patient-centeredness”
52 and hark on the disability justice slogan, “Nothing about us without us” (Iezzoni and Long-Bellil,
53 139). Their commentary reflects the lack of patient-centered care and data, which ultimately informs
54 our discussion of limitations, conclusion, and next steps.

55 Therefore, it is very important to examine the quality of care for individuals with IDD, and
56 how a patient’s age, gender, and a myriad of other demographic factors may lead them to received
57 different standards of care.

58 **Motivation and Research Questions.** Since these studies have established reasonable belief that
59 there is discrimination based on gender and race in the field of healthcare for individuals with
60 disabilities, we decided to pursue our project, in which we will attempt to identify discrepancies in
61 care for those of marginalized demographic groups and other areas of insufficiency in care for those
62 with IDD using data provided by START.

63 In this study, we have decided to pursue two main research questions:

- 64 • To what extent are there discrepancies in quality of care among disable individuals of different
65 races and genders?
- 66 • What services and types of care are most lacking among these demographics, and how do they
67 differ?

68 Data

69 **Acquisition.** The two dataframes that we used were the FEIS dataset, which contained quantitative
70 and qualitative family responses about the patient's care, and the START demographics dataset,
71 which provided us with information about the patients' races and genders. Both datasets were
72 provided by the START program. Due to sample size, our group chose not to subset the data by
73 date, meaning that our time window of data ranges from September 2009 to December 2020. As we
74 needed a metric to determine general quality of care, our units of analysis stemmed from the FEIS
75 survey responses and our variables were gender and race, meaning that we created four separate
76 datasets for each demographic - white males, white females, nonwhite males, and nonwhite female
77 patients. The columns that we used in specifics to analyze differences between these demographics
78 were:

- 79 1. During the past year, in general how satisfied were you with the outpatient mental health
80 services your family member received?
- 81 2. In the past year, did your family member use in-patient psychiatric services?
- 82 3. During the past year, how convenient was it for your family member to use mental health
83 services (i.e. were services easy to access)?
- 84 4. Was there any particular service that your family member needed that was not available?
- 85 5. If yes, please describe the service.
- 86 6. Are there options outside of the hospital for individuals experiencing a crisis to go for help (i.e.
87 crisis/hospital diversion beds)?
- 88 7. What advice would you give to service planners regarding the mental health service needs of
89 persons with IDD and their families?

90 **Limitations in Data.** One key limitation of the FEIS survey responses is that the inputs come not
91 from the patients themselves, but rather from the caregivers. The FEIS categorizes caregivers as
92 being from either the families of the individuals being cared for, patient support staff, or the patient
93 themselves. Although these responses are the closest we will get to analyzing patient satisfaction
94 and need, they are still merely estimates as they stem from caregiver perceptions of a patient's life
95 as opposed to actual patient feedback. Another limitation with this data stems from patients of

unknown race, as all patients whose race was not ‘White’ were inserted into the nonwhite datasets by their respective gender. Our dataset had 53 patients of unknown race, and despite this group being a small proportion compared to the 1097 entries in our data, our group still chose to make this generalization in order to maximize our potential sample size. Additional limitations and their impacts on the study will be analyzed further in the discussion section.

Methods

Data Cleaning. In order to prepare our data, we first looked at the Dartmouth Dataset, which contained various pieces of demographic information on each patient. Since this was a large dataset, we subsetted only to columns with information that we considered to be pertinent to our study, such as Local ID, Gender, Race, Psychiatric Diagnoses, and Medical Diagnoses. However, we primarily focused on race and gender as our main variables to assess differences in family satisfaction. Since our primary units of analysis were the FEIS responses, we also used the FEIS dataset and merged the FEIS dataframe with our cleaned demographic dataframe on the “Local ID” column. We used an inner merge in order to only look at patients whose families responded to the survey, and to drop any data on patients whose families did not. This way, we could perform analysis on a sample of patients who were associated with FEIS data.

Since ID numbers and formatting were consistent across the two datasets, there was no need for fuzzy matching as we were able to easily exact match on Local ID. Then, as detailed above, we divided our merged dataset into our four demographic groups of interest: white male, white female, nonwhite male, and nonwhite female patients. We then subsetted our data to the questions of interest above. To better examine this data, we dropped any null values to make aggregation and topic modeling possible.

Analysis. In order to answer our research questions, we decided that it would be best to split our analysis into two main parts. Part One looks at questions on the FEIS dataset that warranted Yes/No or Likert Scale responses. We then used aggregation to yield numeric representations of satisfaction and quality of care and compared them among our four demographic groups.

Part Two deals with broader family feedback for patient care, so we extracted the top 40 keywords and conducted LDA topic modeling for each subset.

Part 1: Numerical Analysis of Yes/No and Likert Scale Questions. As we first investigated the broader, more numeric metrics of caregiver perception, we measured and compared (1) general satisfaction with outpatient care services, (2) the accessibility of mental health services for patients, (3) the rate of in-patient psychiatric services used during a patient crisis within the past year, (4) the availability of necessary services for patients, and (5) the accessibility of non-hospital options for patient crisis response by our constructed race and gender categorizations.

Outpatient mental health services are defined as mental health services provided for an individual received without their hospital admittance, whereas inpatient psychiatric care is defined by the patient’s admittance to a hospital or treatment center.

For each metric, we grouped responses by the race and gender of the individuals (using the *Race_Gender* identity from the overall *all_race_gender* dataframe) and binary indicators for a given question, or we concatenated our five racial and gender demographic subsetted dataframes (including overall patients) and then once more subsetted based on response instead of demographic. These subsetted answers were then used to create either simple or dodged bar charts to visualize racial and gender discrepancies for each question depending on whether or not there was a binary

139 Yes/No or Likert scaled response. A user-defined function was created to construct simple bar charts
140 (four distinct bars). A user-defined function proved too difficult to create for varying dodged bar
141 charts based off of Likert responses, so the provided code is admittedly redundant. Screenshots
142 of the produced bar charts were saved and uploaded to the outputs folder in the project Github
143 repository.

144 **Part 2: Topic Modeling and Top Words.** As the second part of our research is aimed more at the
145 areas of need that patients face, we conducted an LDA topic model and found the top keywords for
146 the 'Family Advice' column (Column 7) by frequency for each subset. After preprocessing the data
147 in the Advice column, we created a document term matrix that took the frequencies of relevant
148 terms and then created a user-defined function which ran the document term matrix on all inputs of
149 advice, found the most frequent words and inserted the tokenized inputs into a dictionary before
150 running the LDA topic model itself with three topics. This function returned a list of the topics
151 in question, the top 40 words by frequency, the topic model used, the corpus from the dictionary,
152 and the raw text in the dictionary. The last three elements in the list were returned to be used as
153 parameters for our visualization function, which takes these inputs and uses pyLDAvis to create an
154 interactive graph which shows both the distance between the topics and the most frequent words
155 per topic. After conducting our first round of analysis, we found that the stems 'need', 'servic',
156 'famili', 'provid', 'care', and 'would' were extremely prevalent in all datasets and that many of these
157 instances referred more to the caregivers than to the patients, so we did not include them in our final
158 analysis by adding them to our stopwords to best highlight the disparities in patient need between
159 demographics.

160 Results - Words

161 **Part 1.** As shown in Figure 1, families of white patients exhibited more general satisfaction with
162 care than families of nonwhite patients, as defined by the response "Very Satisfied." Among white
163 patients, families of female white patients were more satisfied than male. Parallel to this, among
164 families of nonwhite females, families of nonwhite female patients were more satisfied than those of
165 nonwhite male patients. These results are particularly interesting as although it was expected that
166 nonwhite patients would experience less satisfaction with their care due to the possibility of racial
167 bias and discrimination, it was not expected that female patients would express more satisfaction,
168 due to the issue of gender bias.

169 It is possible that the racial and gender identities of patient caregivers (who are not the patient
170 themselves) influence the satisfaction rating and thus the racial and gender discrepancies observed,
171 but the demographics dataset does not contain any information on the racial and gender identities
172 of caregivers, so it is impossible to observe any correlation.

173 The general satisfaction more broadly reflects large dissatisfaction with outpatient mental health
174 services. Approximately 20% of caregivers overall reported that they were "Very Satisfied," and
175 as Figure 1 demonstrates, the caregivers of patients across all four racial and gender constructions
176 reported the inability to access necessary services for the needs of the disabled individual in their
177 care. Likewise, Figure 3 reflects that for mental health services specifically, only about 20% of
178 caregivers reported that services were "Easy to access." The caregivers of nonwhite female patients
179 reported the highest levels of difficulty accessing ("Difficult to access") mental health services, and
180 the caregivers of male patients reported the highest rates of inability accessing ("Could not access")
181 mental health services with around 10% of responses. Figure 2 shows that in the event of a patient
182 crisis, only 10% of caregivers reported access to "All that was needed/wanted" of non-hospital

183 crisis response options; the only 7.5% of caregivers of nonwhite male patients reported access to all
184 necessary non-hospital crisis response options. The caregivers of nonwhite male and female patients
185 also reported the highest levels of inaccessibility to crisis response options other than hospitalization,
186 with nearly 50% by male patients and 44% by female patients. The sparsity of non-hospital crisis
187 response options reported is corroborated by Figure 5, which shows that over 25% of patients in
188 every racial and gender construction have been placed in in-patient psychiatric services in the past
189 year. For nonwhite female patients, this number is nearly 40%, which could reflect the possibility of
190 racial and/or gender bias in treatment services.

191 **Part 2: Top Words.** Although these top words are indicative of the caregivers' perceptions of the
192 patients instead of the patients themselves, they still garner interesting results concerning the
193 patients' needs depending on their respective demographic. Firstly, as seen in Figure 6, we see that
194 nonwhite females have the keyword 'help' in 7th as compared to the other datasets that rank this
195 word in 1st or 2nd. Furthermore, nonwhite females ranked the keyword 'none' in 1st while the other
196 subsets had this keyword lower down in their lists (from 6th through 12th). Although the caregivers
197 of nonwhite females report the second lowest rate of satisfaction as seen in Figure 1, these rankings
198 may imply that the caregivers of nonwhite females may settle with lower expectations of care or
199 that their loved ones do not need any adjustment. These results sit in stark contrast to some other
200 demographics such as the white female subset, which reported the highest levels of satisfaction but
201 were still very vocal about improvements that support staff could make. However, nonwhite females
202 have the keyword 'listen' in 2nd while all other subsets feature this keyword in around 17th (or
203 not at all for white females), possibly implying that caregivers wish for support staff to be more
204 receptive to their loved ones' needs.

205 Another interesting result is that white females did not have the keyword 'access' in their top
206 40 while all other subsets featured it in 10th, 14th, and 16th. While access is not a highly ranked
207 keyword, we may be able to imply that the families of white females feel less need to demand access
208 to care or services for the individuals in question.

209 Finally, we see that there are a few disparities between subsets in gender, as both male datasets
210 have the keywords 'individu' (implying 'individual') and 'crisi' (implying 'crisis') in their top 40
211 while the female subsets do not. Although 'crisi' is more ambiguously ranked, with white males
212 ranking it in 3rd and nonwhite males ranking it in 26th, both male datasets ranked 'individu' in
213 4th and 2nd, highlighting a disparity in perceived patient needs. One possible suggestion for this
214 contrast is that the families of male patients may pay more attention to the patient's needs as an
215 individual person, while families of female patients may intertwine the patient's needs more with
216 their own.

217 **Part 2: Topic Modeling.** During the second part of our analysis, where we conducted topic modeling
218 on all subsets, we removed words that were relevant in every subset enough to find a general
219 distinction between the topics as seen in the analysis section above. In regards to the general dataset,
220 the three topics we analyzed primarily focused on interpersonal support, staff accommodations
221 for patient needs, and access to resources and information. For clarification, responses related to
222 interpersonal support pertain to staff's ability to understand patient and family requests, while we
223 define responses relating to staff accommodation as the staff's solutions to said requests. We came
224 to these conclusions as the first topic featured keywords such as 'help', 'support', and 'avail', the
225 second topic had words like 'answer', 'time', and 'understand', while the third topic was focused on
226 words such as 'inform', 'resourc', and 'access' as seen in Figure 4a.

227 One interesting observation is that Topic 3 of the white male dataset made up a separate category

entirely, as seen in Figure 7c, as it focused primarily on time commitment and staff coordination of care. Instead of keywords such as ‘resource’ or ‘inform’ as we see in some other subsets, this topic is made up of the keywords ‘earli’ and ‘coordin’ as well as ‘time’, meaning that the white male subset may be concerned with the amount of time staff invest in their care significantly more than all other subsets. Two examples of family responses which had a high likelihood of falling within this topic are shown below.

“Take time to build rapport with [the patient]”

“Need to be more timely”

Apart from this particular topic, most other topics in the subsets roughly fell under the topics found in the entire dataset. As interpersonal support for patients and staff accommodations for needs are closely related conceptually despite being equidistant from the third topic (information and resources), we also observed a lot of overlap between these two topics in each subset (see Figures 4b-4e). For instance, Topic 3 for nonwhite females and Topic 2 for nonwhite males fall under access to resources and information, while Topic 3 for white females falls under staff accommodation and both topic 1 and 2 for white males overlap between staff accommodation and interpersonal support.

Results - Graphs and Figures

Part 1. Visuals for Part One of Analysis

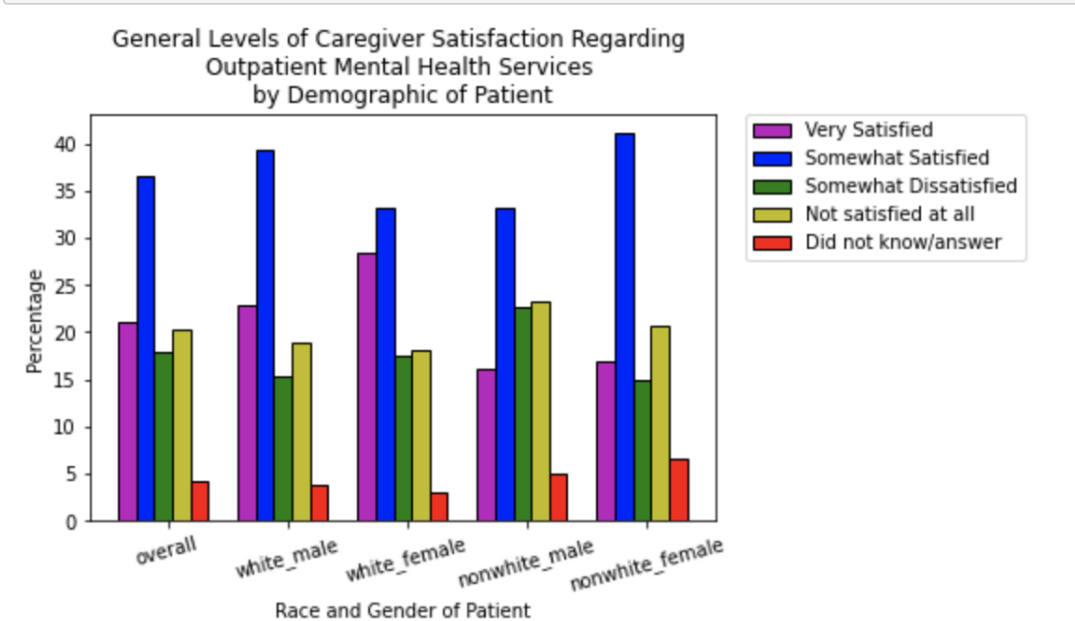


Fig. 1. Caregiver responses to question "During the past year, in general how satisfied were you with the outpatient mental health services your family member received?" based on a Likert scale rating, aggregated by race and gender of patient

Caregiver Reporting of Accessible Non-Hospital Crisis Response Options
by Patient Demographics

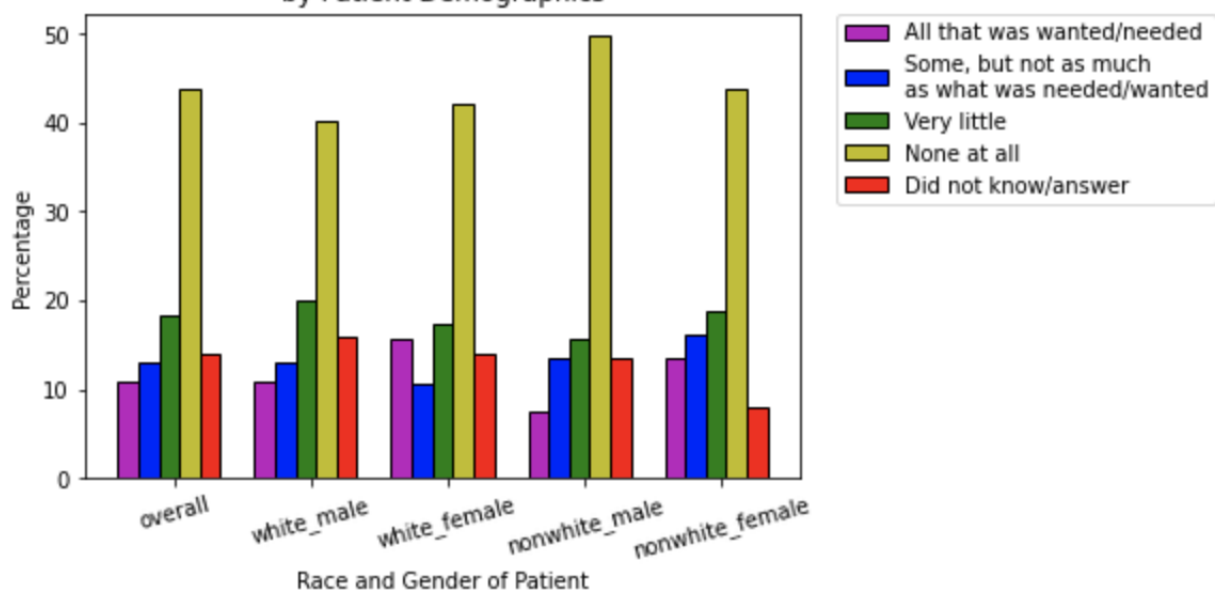


Fig. 2. Caregiver responses to question "Are there options outside of the hospital for individuals experiencing a crisis to go for help (i.e. crisis/hospital diversion beds)?" based on a Likert scale rating, aggregated by race and gender of patient

Caregiver Reports of Accessibility of Mental Health Services
by Patient Demographics

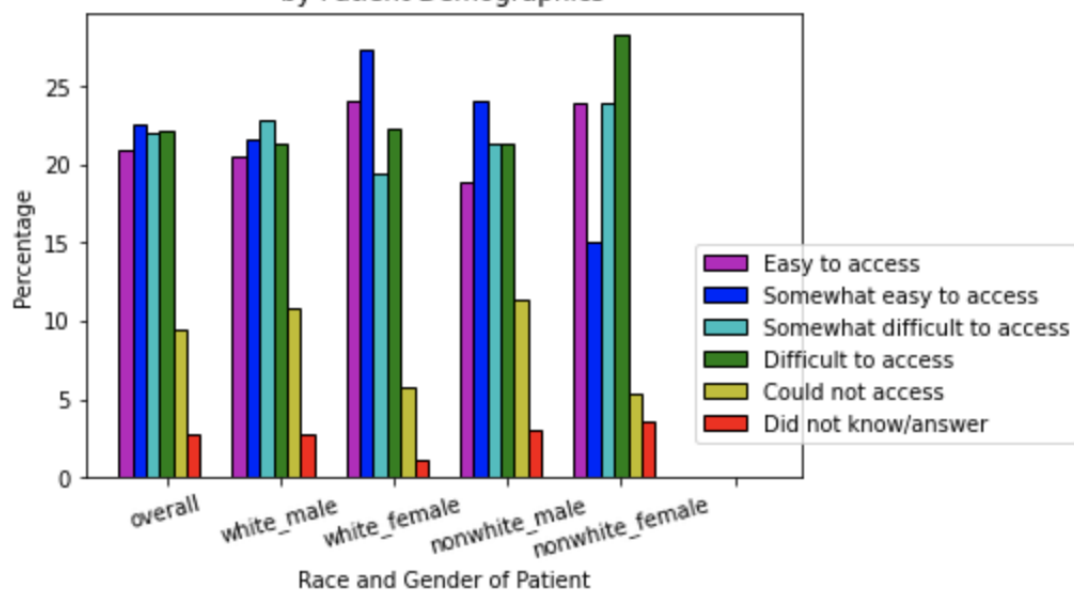


Fig. 3. Caregiver responses to question "During the past year, how convenient was it for your family member to use mental health services (i.e. were services easy to access)?" based on a Likert scale rating, aggregated by race and gender of patient

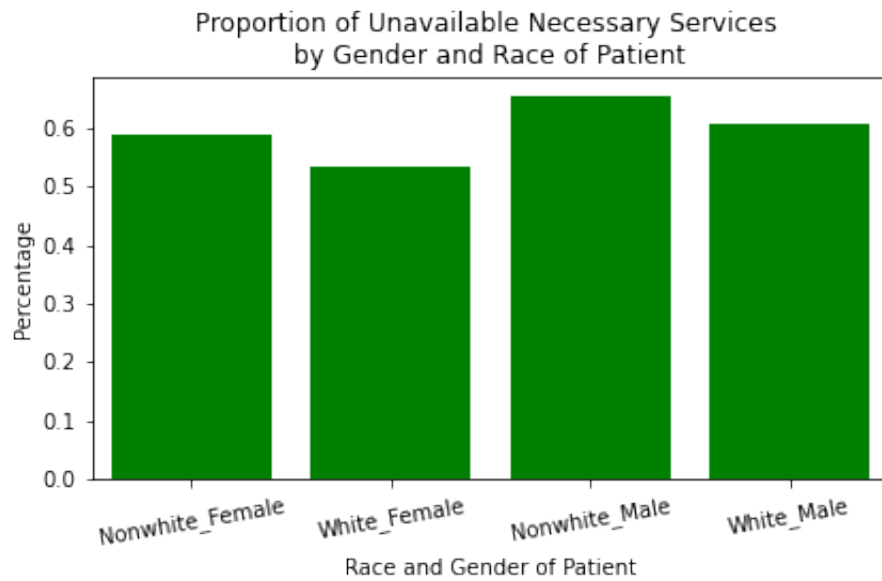


Fig. 4. Percentage of caregivers who responded "Yes" to the question "Was there any particular service that your family member needed that was not available?" with responses grouped by race and gender of respective patients

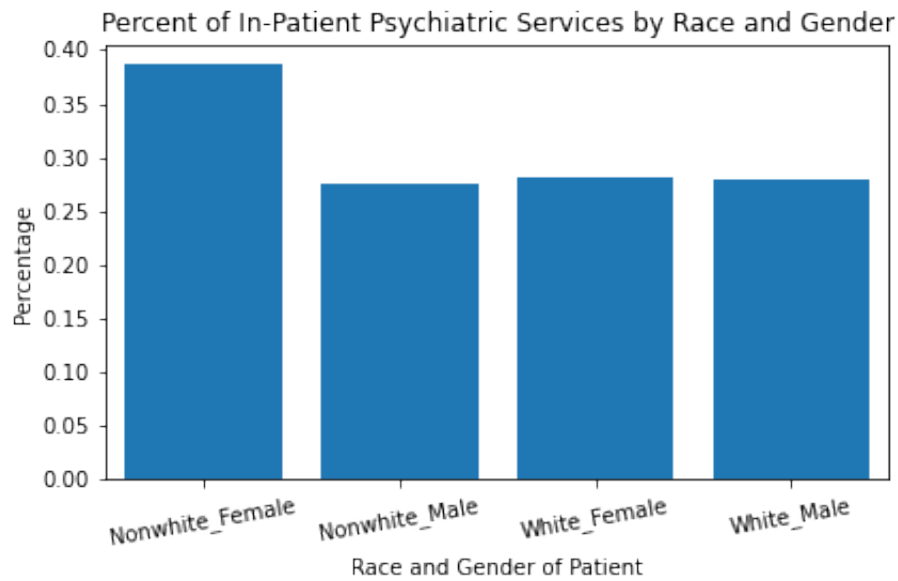


Fig. 5. Percentage of caregivers who responded "Yes" to the question "In the past year, did your family member use in-patient psychiatric services?" with responses grouped by race and gender of respective patients

Keywords	Rank_Overall	Rank_FW	Rank_MW	Rank_FNW	Rank_MNW
help	1	1	2	7	1
support	2	9	1	4	8
none	3	7	12	1	4
individu	4	NR	4	NR	2
answer	5	15	9	3	12
avail	6	18	5	NR	11
get	7	16	7	12	9
time	8	26	13	22	3
inform	9	2	20	6	13
parent	10	NR	8	19	10
listen	11	NR	19	2	17
peopl	12	10	11	15	15
make	13	11	35	5	6
access	14	NR	10	14	16
take	15	NR	21	11	5
resourc	16	25	15	20	21
understand	17	17	26	NR	7
crisi	18	NR	3	NR	26
nt	19	32	6	NR	NR
work	20	34	14	38	34
health	21	5	NR	35	19
medic	22	4	23	NR	40
know	23	NR	16	9	NR
idd	24	14	27	NR	27
member	25	12	29	10	NR
mental	26	21	NR	21	20
better	27	8	NR	NR	25
like	28	NR	24	NR	24
option	29	NR	17	NR	NR
go	30	36	NR	NR	14
children	31	NR	18	NR	22
person	32	28	22	NR	NR
sure	33	23	NR	NR	37
home	34	NR	NR	32	39
respit	35	NR	36	NR	18
give	36	NR	34	NR	35
find	37	3	NR	NR	NR
child	38	29	NR	NR	NR
one	39	NR	32	NR	33
lot	40	40	30	NR	NR

Fig. 6. Table listing the top 40 keywords found in the overall dataset, as well as the ranks for those words among the four subsets analyzed (FW - White females, MW - White males, FNW - Females of color, MNW - Males of color). "NR" means that the keyword was not ranked in the subset specified.

Topic 1	Topic 2	Topic 3
help	none	inform
support	answer	access
listen	time	help/support
individu	understand	mental
avail	crisi	resourc

(a) All Patients

Topic 1	Topic 2	Topic 3
help	inform	none
find	system	medic
health	peopl	time
support	medic	get
make	dysregul	appoint

(b) White Female Patients

Topic 1	Topic 2	Topic 3
help	support	earli
avail	answer	like
crisi	individu	peopl
support	work	time
none	member	coordin

(c) White Male Patients

Topic 1	Topic 2	Topic 3
support	help	none
member	behavior	answer
profession	make	infor
know	listen	listen
discourag	peopl	mental

(d) Nonwhite Female Patients

Topic 1	Topic 2	Topic 3
individu	none	time
answer	inform	listen
help	understand	get
peopl	avail	support
respit	access	parent

(e) Nonwhite Male Patients

Fig. 7. Top Relevant Words by Topic

Discussion

Limitations. The primary limitation of this study is that our current method of measuring patient satisfaction comes from the families of the patients rather than the patients themselves. Although families are in most cases the closest contacts to the individuals in question, we have no way to gauge the real extent to which patients rate their care. Additionally, some of the top words that are meant to indicate areas of need for patients actually stemmed from the needs of family members themselves. For example, the word ‘care’ was originally thought to refer to the patient, but many instances of this keyword were linked to ‘caretaker’ or ‘caregiver’ instead. Thus, we had to sift through the words listed in order to confirm that most were linked to the patient.

Another limitation of this study is the size of the datasets themselves, as we decided to inner merge to make sure every patient included had advice from their caregivers. After subsetting based on demographic information, we found that certain groups such as women of color had significantly less entries than those of any other dataset, making the results of this demographic more prone to being skewed or the opinions being inaccurate. Due to the limited size of the datasets, we also decided not to subset based on location, meaning that this study does not account for geographic or regional differences and is instead a generalization of patient care across the U.S.

Next Steps. Possible next steps for our analysis should seek to break down the data and observe it on an increasingly granular level. One step that could be taken would be to further separate the non-white demographics of our dataset into specific racial minorities; for example, we may be able to observe disparities between respondents on behalf of Black, Latinx, Asian-American, and multiracial patients. Another step could be investigating changes in sentiments and keyword frequency since the advent of the COVID-19 pandemic in order to determine possible effects the pandemic had on the healthcare of disabled individuals. Other next steps would include implementing a variety of topic models besides the LDA model. Due to time constraints, we were not able to run other topic models, but ones that might yield illuminating results include the text frequency-inverse document frequency (TF-IDF) topic model and the Frequency and Exclusivity Words (FREX) topic model. The TF-IDF topic model allows us to define customizable topics, which would have provided us with an opportunity to leverage domain knowledge when constructing the topic model. The FREX model attempts to find words that are both frequent in and exclusive to a topic of interest and could

275 have reduced our issue with the LDA topic model of the same keywords being redundant across
276 multiple topics.

277 In regards to the START program, actions that could be implemented to more accurately measure
278 the degree of patients' care are firstly to get more data overall for a larger sample size and also to
279 obtain more data from the patients themselves. Action should be taken to ensure that patients have
280 maximum access to any and all assistive technologies and systems for communication are provided,
281 and that all patients consent to interviews. The data from such interviews could drastically qualify
282 the results of this study. Moreover, many of the limitations we encountered in this study were
283 connected to the fact that there was no ideal metric for assessing the quality of care for each patient.
284 We decided upon examining the FEIS responses, but these can be inaccurate or biased, and on
285 top of that, not every family responded to every question in the survey, limiting our sample size.
286 However, any amount of input from the individuals enrolled in the program is valuable information
287 and is more accurate than the comments the family provides as they are not enrolled themselves.

288 Conclusion

289 Through this study we have found statistical evidence that may indicate discrepancies in care for
290 individuals with IDD based on race and gender. We have also identified specific areas that the
291 analyzed demographics still desire when it comes to care of individuals with disabilities through
292 topic modeling and frequency analysis. However, we have also established the need for further data
293 collection and research in this field as we faced many limitations through the study. Ultimately,
294 extremely low genuine satisfaction ratings, poor accessibility and availability of mental health and non-
295 hospital crisis response services, and high instances of inpatient hospitalization and institutionalization
296 reported by caregivers indicate distinct shortcomings of the current policies, procedures, and
297 organization of the START Program. Immediate steps towards rectifying current practices should
298 take place. Perhaps one starting point for revision could be a greater focus on meeting the 6 core
299 competencies for physicians care of disabled patients as proposed by Kirschner and Curry (1134):

- 300 1. a conceptual framework of disability in the context of human diversity, illness, the life span,
301 and the constructed social and cultural environments;
- 302 2. skills for assessing the level of disability, the functional consequence of illness, and the social
303 and physical environments of patients with disabilities along with considerations for treatment
304 and management;
- 305 3. general principles and etiquette for interacting with persons with disabilities;
- 306 4. appropriate knowledge about interdisciplinary clinical care teams, the different roles and
307 functions of various team members, and other disability-specific resources in both the health
308 care system and the community;
- 309 5. the legal requirements of the Americans with Disabilities Act in health care and the concepts
310 of universal design— not just for the built environment, but for all aspects of patient-related
311 care, including medical equipment, staff procedures and training, and communication practices;
312 and
- 313 6. patient-centered care and the importance of understanding quality of life from patients'
314 perspectives.

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