# Understanding Suicide Risk and Patient Portal Use in Patients with Autism Spectrum Disorder

By

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## NOTE ON INCLUSIVITY

Ongoing discussion exists on how to best refer to individuals with autism spectrum disorder (ASD) in an inclusive and non-ableist manner. Some stakeholders prefer "person-first" language (e.g. individual with ASD) and others prefer "identity-first" (e.g. autistic individual)[1,2]. Preference of every individual person should be respected; however, the purpose of this paper is not to resolve consensus on how to refer to the community. While acknowledging this lack of consensus, we believe it is more conservative to refer to our cohort using "person-first" language which will be the terminology used for the remainder of this paper.

## INTRODUCTION

Approximately 2.2% of the U.S. adult population has ASD[3] which is characterized by deficits in social communication and restricted or repetitive behaviors or activities according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition[4]. A large retrospective cohort study found that individuals with ASD had approximately three times higher rates of suicide attempt and suicide compared to all other individuals[5]. A similar study accounting for intellectual disability (ID) and attention-deficit/hyperactivity disorder (ADHD) diagnosis found a 4 (without ADHD) to 7 (with ADHD) times higher attempted suicide risk amongst individuals with ASD without ID to the general population[6]. One study found 8.9% of adult individuals with ASD had a suicide attempt within the last year and 48.7% had a suicide attempt at some point in their life[7]. The ASD population has elevated levels of suicidal thoughts and behaviors.

Even though this population is at increased risk for suicide, efforts to detect and prevent suicide are complicated by various factors. Some of this could be due to the social-emotional differences that characterize ASD affecting provider-patient interactions[4]. For example, one study found that only half of the individuals (8/16) with ASD presenting to a psychiatric emergency room with STB identified their STB as their 'chief complaint', allowing the health care provider to immediately address the issue[8]. Those that did not immediately identify STB as their chief complaint originally presented seeking support for other issues such as "financial crisis, diagnostic clarification, psychiatric evaluation after assaulting someone, request for medication, and medication review"[8]. Another study found significantly endorsed reason for non-disclosure by people with ASD was "I wasn't sure how to express my thoughts"[9]. Additionally, individuals with ASD commonly have co-occurring conditions such as alexithymia[10], ID[11], and limited verbal abilities[12] which could affect their ability to communicate suicidality with others. Some of this difficulty in suicide risk assessment could also be on the provider end due to diagnostic overshadowing, or clinicians overlooking some symptoms to find what they are looking for, even though it might not be the most accurate diagnosis. For example, the social communication differences and atypical presentation of depression in individuals with ASD, may cause providers may overlook depression symptoms and attribute them to ASD[13,14]. The opposite also occurs where providers assume an individual has a mood or anxiety disorder and misses signs of ASD[13]. There is a need for more objective methods for assessing suicide risk, especially in the ASD population.

Currently there is a lack of objective, robust, and scalable methods for assessment and prediction of suicide in an ASD population. To date and to my knowledge, two tools have been developed and published for suicide risk assessment specific to an ASD population[9,15]. However, these tools have been developed and validated exclusively in a research setting (not assessed in clinical setting); they simply assess past experience (not predict future attempt), and they are unable to be used by those with ID. Questionnaire tools such as these inherently have a social interaction component which may not be best suited for individuals with ASD. Suicide has historically been difficult to predict[16], yet without robust characterization and assessment of suicidality in ASD, this prediction task becomes nearly impossible. Electronic health record (EHR) data can provide a more objective, robust, and scalable way to characterize, identify, and predict suicide. Additionally, because ASD has many physical and mental health comorbidities[17], the ASD population tends to be high users of healthcare[18–20], meaning they will have more robust and complete EHR data than populations who use healthcare less.

Vanderbilt University Medical Center (VUMC) currently has two EHR-based resources which may prove useful in the identification of suicide amongst patients with ASD. One is Vanderbilt Suicide Attempt and Ideation Likelihood (VSAIL), which is an EHR-based random forest model which currently outputs a calibrated probability 30 day suicide attempt risk score for all patients at VUMC[21–23]. The model uses 600 predictors from the patient's last 5 years of structured EHR data at VUMC. Model features include demographics (age, sex, race), area deprivation index based on zip code[24], diagnoses grouped into hierarchical condition categories, medications categorized to their anatomic therapeutic classification level IV, and healthcare utilization as described by current procedural terminology codes. Through this project, we hope to learn about VSAIL's performance in an ASD population. We hope that by studying suicidality through the EHR, it will allow for a more objective lens to characterize suicidality in ASD. Another EHR-based tool at VUMC that may prove useful in the identification of suicide risk is My Health at Vanderbilt (MHAV). MHAV is a patient portal system at VUMC where patients can message their doctors. Patient messages can be mapped back to their EHR to report outcomes such as suicide attempt (something a suicide hotline or online forum cannot necessarily do). Using this, we hope to characterize patients that do and do not message their doctors via MHAV. Additionally, because both VSAIL and MHAV are EHR-based, they theoretically can easily be scaled to larger populations (such as people without ASD) and possibly exported to other medical centers. For example, through these projects we are focusing on adults with ASD, as they have historically been underrepresented in research[25], but our results in adults may be able to be translatable to pediatric populations. Through improved identification of suicide risk in patients with ASD, we hope to be able to better connect patients with ASD experiencing suicidal thoughts or behaviors to needed care.

# CHAPTER 1: EXTERNAL VALIDATION OF SUICIDE RISK PREDICTION MODEL FOR PATIENTS WITH AUTISM SPECTRUM DISORDER

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Background and Significance

The CDC estimates that 1 in 44 children and 2.2% of adults in the U.S. have autism spectrum disorder (ASD)[3,26]. ASD is characterized by deficits in social communication and restricted or repetitive behaviors or activities according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM 5)[4]. Estimates suggest both adults and children with ASD are over three times as likely to engage in suicidal thoughts and behaviors compared to the general population[27]. One study found that 8.9% of adult patients with ASD had a suicide attempt within the last year and 48.7% had a suicide attempt at some point in their life[7]. Another found 8.3% of children with ASD had suicidal attempts[28] and a larger study found that 4% of all deaths in the ASD population occurred by suicide[29]. In addition to the high suicide rates, people with ASD are more likely to engage in healthcare settings, both inpatient and outpatient, with longer length of stay than the general population[18–20,30–33]. This is attributed to their higher prevalence of physical and mental health comorbidities[17,34]. This high healthcare utilization could allow for preventative efforts; however, we currently lack a robust understanding of suicide risk factors and tools to identify suicide risk in ASD.

Suicidal thoughts and behaviors are often missed in the ASD population due to dispositions of both patients and providers[13]. Diagnostic overshadowing is when a clinician may overlook depression symptoms due to an existing ASD diagnosis[13,35]. More frequently the opposite occurs where providers diagnose mood and anxiety disorders while overlooking possible ASD diagnosis[13,36,37]. In two separate case studies, the patient was not diagnosed with ASD until after their suicide attempt[38,39] and one study found that most of their patients were not aware of their autistic traits at their first visit to the clinic[40]. Confounding the difficulty in diagnosis is the societal expectation that autistic patients should "mask" or "camouflage" their autistic traits. This masking is exhausting for patients and is associated with poor mental health, including suicidal thoughts and behaviors[13,41–43]. Beyond camouflaging, several suicide risk factors are specific to the ASD population. Part of the characterization of ASD includes "highly restricted, fixated interests that are abnormal in intensity of focus"[4], often referred to as rumination. This rumination is associated with suicidality within the ASD population[8,39,44]. Other identified risk factors in the ASD population are different than those in the general population further complicating identification for diagnosis[5].

Differences in social communication and social interaction are characteristic of ASD[4]. This can present as "reduced sharing of emotions or affect" and/or "total lack of facial expressions and nonverbal communication"[4,14,39,45]. These social communication difficulties highlight the need for ASD studies and suicidality assessments to utilize fewer verbal and non-verbal inputs. Although DSM 5[4] removed language difficulties as a core ASD feature, about 25% of children with ASD are nonverbal[12]. Further compounding this inability to communicate is the fact that approximately half of persons with ASD have co-occurring alexithymia, the unawareness of feelings corresponding to emotions or the inability to verbalize emotions[10]. Although current research shows that mediating alexithymia can improve mood disorders in ASD[46,47], persons with alexithymia have a difficult time understanding their own emotions to the point where they are

unable to ask for and receive help[5,12,13,20,21,23,26]. Chart review of suicidal patients with ASD to an emergency department, revealed that only half of them claimed suicidal thoughts and behaviors as their chief complaint[8]. Similarly, through the development of suicidal questionnaire for persons with ASD, 43% of patients never disclosed their suicidal thoughts or behaviors to another[9]. ASD suicidality research should focus on situational adjustments of the patient due to the difficulty persons with ASD experience communicating their emotions both verbally and nonverbally. Additionally, because suicidality in individuals with ASD looks similar to suicidality for individuals in the general population, it may be best to monitor changes in the person's behavior or situation[8,10,14,35,38,45,48–50].

Additionally, while some risk factors of suicidality have been identified in the ASD population, many require in-depth questioning about the patient's situation that can be difficult to identify. There is a need for more objective methods for assessing suicide risk, especially in the ASD population. Currently there is a lack of objective, robust, and scalable methods for assessment and prediction of suicide in an ASD population. To date and to my knowledge, only two tools have been developed and published for suicide risk assessment specific to an ASD population[9,15]. However, these tools have been developed and validated exclusively in a research setting (not assessed in clinical setting); they simply assess past experience (not predict future attempt), and they are unable to be used by those with ID. Questionnaire tools such as these inherently have a social interaction component which may not be best suited for individuals with ASD. Suicide has historically been difficult to predict[16], yet without robust characterization and assessment of suicidality in ASD, this prediction task becomes nearly impossible. Electronic health record (EHR) data can provide a more objective, robust, and scalable way to characterize, identify, and predict suicide.

Individuals with ASD may require a tailored model, but before undertaking novel model development, we sought to evaluate how an existing prospective suicide risk prediction model, collecting patient information in the background-without user input, designed to support clinical decision making in a general population provides clinically useful performance for patients with ASD. The objective of this study is to validate an existing suicide risk prediction tool for an ASD population.

## Methods

### Clinical Predictive Modeling/Clinical Phenotyping

Walsh et al[21,51] developed and implemented, the Vanderbilt Suicide Attempt and Ideation Likelihood (VSAIL) model that predicts likelihood of suicide attempt at Vanderbilt University Medical Center (VUMC), a major academic medical center in the mid-south. VSAIL was trained on data at VUMC and first deployed in June 2019 to run in the background for adult patients in inpatient emergency and surgical settings only. In February 2021, the model's use expanded to run in the background for all adult patients visiting VUMC, inpatient or outpatient. When a patient registers for a visit, 600 features from their electronic medical record (EHR) are collected based on the previous 5 years of data for the patient. Model features include demographics (age, sex, race), area deprivation index based on zip code[24], diagnoses grouped into hierarchical condition categories (HCC), medications categorized to their anatomic therapeutic classification (ATC) level IV, and healthcare utilization as described by current procedural terminology (CPT) codes. The features are fed into the random forest model which outputs a calibrated probability risk score (between 0 and 1 inclusive with 1 being the highest risk) of estimated future suicide attempt risk.

Subjects

The objective of this paper is to evaluate VSAIL model performance, without additional training, for patients with autism spectrum disorder between June 2019-August 2021. For analysis, each prediction is treated independently. Suicidal ideation, thought, or behaviors (STB) were associated with a prediction if there was an Internal Classification of Diseases-Ninth or Tenth Revision-Clinical Modification (ICD-9-CM or ICD-10-CM) STB code within 30 or 90 days after the prediction was calculated. STB codes were selected from Supplementary Information, Tables S3 and S4[52] with additional ICD 10 codes of X60-X70, X84, and Y10-Y20. Patients were included in study if patient had at least one VSAIL prediction and two or more ICD-9-CM or ICD-10-CM codes of autism [F84.0, 299.00], Asperger syndrome [F84.5, 299.00], and/or pervasive developmental disorder (PDD) [F84.9, 299.90]. These ICD codes were selected based on the consolidation of autism, Asperger Syndrome, and pervasive developmental disorders not otherwise specified (PDD) into ASD as specified in the newest diagnostic and statistical manual of mental disorders 5 (DSM 5)[4].

Data Analysis

ASD cohort and suicidality in cohort was characterized using descriptive statistics. Statistical analyses include t-tests and chi-squared tests of the patients with/without suicidal thought or behavior (STB) ICD codes to elucidate possible risk factors for suicidality within cohort. Number of patients with intellectual disability was determined using ICD codes given in any point in time in the patient's record at VUMC. ICD-10-CM codes for ID were F70, F71, F72, F73, F78.*, F79[21] and ICD-9-CM codes for ID were 317, 318.*, 319[22]. Model output was characterized. Model feature importance was analyzed by considering the predictors with the highest values in each of the HCC and ATC categories amongst: predictions in the highest risk quantile as calculated by the model, predictions with STB codes associated, and the absolute difference in predictions with/without STB codes associated. Model-predicted stratification of BMI, area deprivation index, and age was also considered. Model performance was measured through area under receiver operator curve (ROC), area under precision recall curve, and Brier scores. These values were compared to a previous evaluation of the model[21] in a general population. The optimal predicted risk threshold for screening consideration in ASD patients was selected by maximizing sensitivity and specificity, whilst maintaining a feasible number needed to screen.

Results

Cohort Description

The 1288 patient cohort had 7979 total predictions between June 2019 and August 2021. 225 (2.82%) of the predictions had documented ICD-9/10-CM suicidal ideation and 46 (0.58%) had documented ICD-9/10-CM suicidal behavior associated within 30 days of the prediction. There was a total of 1011 (66.9%) suicidal ideation and 500 (33.1%) suicidal behavior ICD-9/10-CM codes documented for the cohort between June 2019 and August 2021. 970 (75.3%) patients had more than one prediction; 318 (24.7%) patients had only one prediction.

4.2% (842/20,085) of all patients at VUMC with an ICD-10-CM suicidal ideation code also had one of the ICD-10-CM ASD codes. 376 (29.2%) patients had at least 1 intellectual disability ICD code at some recorded time (could be outside June 2019-August 2021 time frame). Amongst cohort between June 2019 and August 2021, 136 (10.6%) patients had ICD-9/10-CM suicidal ideation code, 35 (2.7%) had suicidal behavior code, and 142 (11.0%) had either a STB code. 1146 (89.0%) patients had no STB code. All-time suicidality in the cohort consisted of 220 (17.1%) patients

having a suicidal ideation code at some point in time. 105 (8.2%) patients having a suicidal behavior code at some point in time, 237 (18.4%) patients having either a STB code at some point in point. 1051 (81.6%) of patients had neither STB code. **Figure 1** depicts the overlap of patients with suicidal thoughts and behaviors.

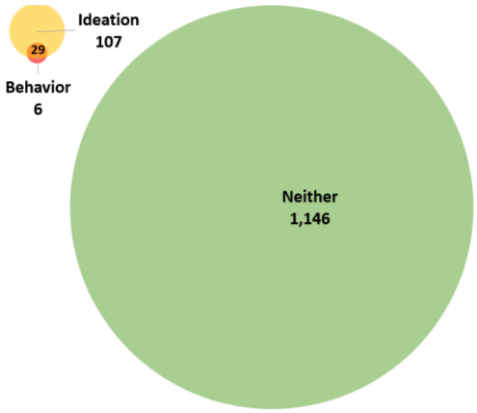


***Figure 1:*** *Venn diagram of patients with suicidal ideation, behavior, or both codes between June 2019 and August 2021*

**Table 1** details ASD diagnoses received in the cohort. Selecting the ASD diagnosis with the highest number of codes to be the primary diagnosis for each patient, primary ASD diagnosis is ascertained. The chi-squared difference between the patients with STB codes and the patients without STB codes of these primary diagnoses was considered insignificant (p=0.16). Sex distribution is contained in **Table 1** with chi-squared analysis on the patients with STB codes and the patients without STB codes yielding insignificant distribution (p=0.27). Similarly, race distribution described in **Table 1** yields a chi-squared test with insufficient evidence for a difference in race distribution between patients with STB codes and those without (p=0.27).

***Table 1:*** *ASD Diagnosis Distributions (all and primary), Sex distribution, and Race distribution*

| | **Autism** | **Asperger Syndrome** | **PDD** | **Analysis** |
|---|---|---|---|---|
| **ASD Diagnoses** | 1126 (87.4%) | 439 (34.1%) | 125 (9.7%) | |
| **Primary diagnosis** | 1024 (79.5%) | 221 (17.2%) | 43 (3.3%) | Chi-squared |
| **Primary diagnosis amongst patients with STB codes** | 186 (78.5%) | 47 (19.9%) | 4 (1.7%) | p = 0.16 |
| | **Male** | **Female** | **Unknown** | **Analysis** |
| **Sex** | 868 (67.4%) | 420 (32.6%) | 0 (0.0%) | Chi-squared |
| **Sex amongst patients with STB codes** | 152 (64.1%) | 85 (35.6%) | 0 (0.0%) | p = 0.27 |
| | **White** | **Black** | **Neither white, black, or unknown** | **Analysis** |
| **Race** | 1033 (80.2%) | 143 (11.1%) | 112 (8.7%) | Chi-squared |
| **Race amongst patients with STB codes** | 196 (82.7%) | 26 (11.0%) | 15 (6.3%) | p=0.27 |

**Figure 2a** below contains the age distribution of the cohort. Running t-test on age yielded evidence of a significant difference between the patients with/without STB codes (p = 0.001). The patients with STB codes had an average age of 26.2 years and patients without STB codes had an average age of 28.5 years. **Figure 2b** below contains the distribution of the patient' age at the time of their first ASD code for the total population and the population with STB codes. There was not a significant difference between patients with/without STB codes using t-test (p = 0.38). Sub-analyses of autism, Asperger's, and PDD yielded insignificant distributions between the patients with/without STB codes using critical value of 0.01.

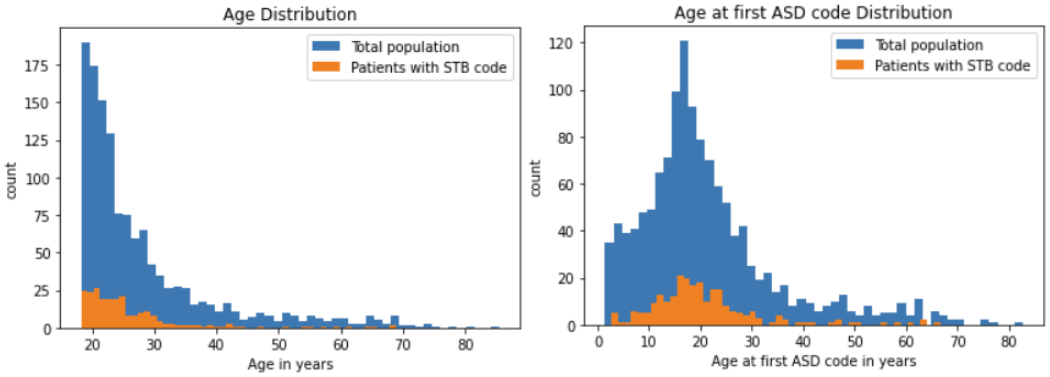


***Figure 2:*** *(a) Age distribution of the total population and the suicidal population (b) Age at ASD diagnosis distribution*

**Figure 3** below shows the distribution of the number of unique visits each for each patient. The t-test difference in the distributions was found to be significant (p= 0.003) with the patients without STB codes group having an average 119 visits compared to an average of 159 documented visits for the patients with STB codes.

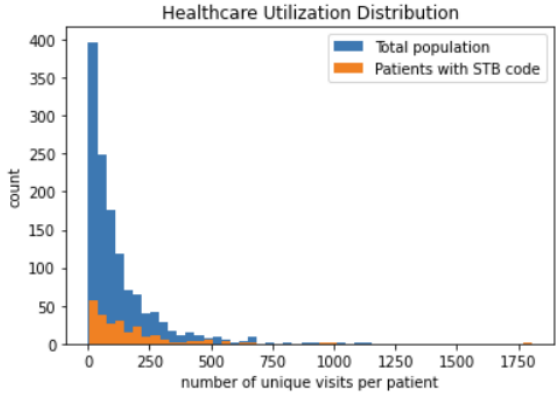


***Figure 3:*** *Distribution of the number of unique visits for each patient*

**Figure 4** below is a histogram of the number of days before each patient's first suicidal ideation or behavior code before the patient received their first ASD code. 116 of 237 patients (48.9%) received STB code before ASD code. Upon chart review of a few patients that received a suicidal ideation code before they received an ASD code, there was evidence in the notes of suspected ASD recorded in the notes although it was not coded for in the ICD billing. A number had "adjustment disorder" in the ICD codes, while notes documented concern for ASD.

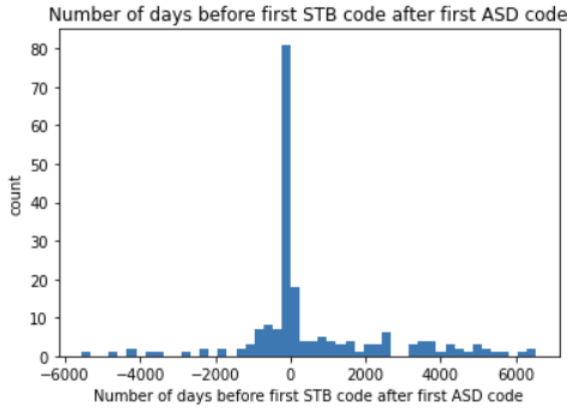


***Figure 4:*** *Histogram of the number of days before first suicidal code after first ASD diagnosis*

The most common suicidal behavior for the cohort between June 2019 and August 2021 consisted of "poisoning by selective serotonin reuptake inhibitors" with 56 (11.2%) documented. This was followed by 39 (7.8%) documented "poisoning by local antifungal, anti-infective and anti-inflammatory drugs" and 37 (7.4%) "intentional self-harm by other specified means".

Model Output

Model considers anything above 2-3% to be "high risk". The average predicted score was 1.5% with a 0.03% variance. The maximum predicted score was 21%. For the predictions with behaviors associated with them, the range was 0.3-8.5% with an average 3.6% and median 3.7%. T-test on the difference in the predicted values for the predictions with and without behaviors associated yielded a significant result ($p < 0.001$). For the predictions with ideations associated with them, the range was 0-9.8% with an average 3.0% and median 3.0%. T-test on the difference in the predicted values for the predictions with and without ideations associated yielded a significant result ($p<0.001$). **Figure 5** below shows the distribution of the probability scores.

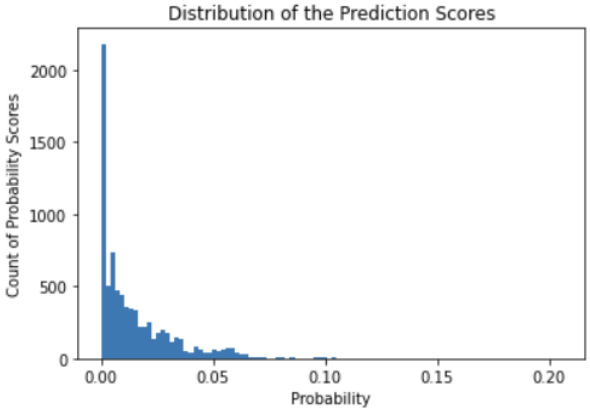


***Figure 5:*** *Distribution of the probability score values*

The model stratified the predictions into four risk quantiles. The highest average predictor value in the highest predicted risk group for ATC codes was found to be "other antiepileptics in ATC" followed by "corticosteroid nasal preparations for topical use" and "other antidepressants in ATC". The highest average value of predictors for predictions with suicidal behaviors or ideations

associated included “other antiepileptics in ATC” followed by “selective serotonin reuptake inhibitors” and “diazepines, oxazepines, thiazepines, oxepines, antipsychotic drugs”. The predictors with the largest average absolute difference between the suicidal and non-suicidal predictions were “diazepines, oxazepines, thiazepines, and oxepines antipsychotic drugs”, “corticosteroid nasal preparations for topical use”, and “osmotically acting laxatives”.

Repeating this analysis with HCC codes, the highest average predictor value in the highest predicted risk group for HCC codes was found to be “major depressive bipolar and paranoid disorders” followed by “seizure disorders and convulsions” and “major depressive bipolar and paranoid disorders reactive and unspecified psychosis”. The highest average value of predictors for predictions with suicidal behaviors or ideations associated included “major depressive bipolar and paranoid disorders” followed by “major organ transplant or replacement status” and “seizure disorders and convulsions”. The predictors with the largest absolute average difference between the suicidal and non-suicidal predictions were “major organ transplant or replacement status”, “major depressive bipolar and paranoid disorders”, and “diabetes without complication”.

Model predicted stratification indicated an increased suicidal risk with lower average BMI and age. There was no clear relationship for area deprivation index between the risk quantiles, but the lowest average area deprivation score was for the highest suicide risk quantile.

Model Performance

The area beneath the ROC curve for predicting suicidal behavior was 0.85 and suicidal ideation was 0.77. Area beneath the precision-recall curves were 0.02 for behavior and 0.07 for ideation. Brier scores for model were 0.006 for behavior and 0.03 for ideation.

Stratifying the predictions into four risk quantiles based on the prediction score, the number of predictions with suicidal behavior and ideation associated with them were calculated to generate **Figure 6** below. The risk threshold between the highest quartile and the lower quartiles was found to be at 2.3% calculated risk score. The sensitivity of this risk threshold was 0.69 for ideation and 0.87 for behavior. Specificity was 0.76 for both ideation and behavior.

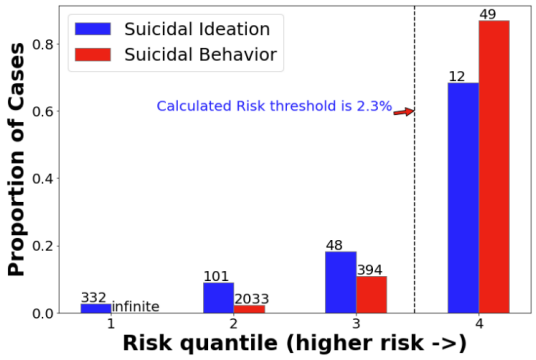


***Figure 6:*** *Proportion of suicidal ideation and behavior groups in each quantile represented by bar. Above each bar is the number of patients needed to screen (reciprocal of positive predictive value)*

**Table 2** below contains the number of true positives, true negatives, false negatives, and false positives for the prediction values using the specified threshold of 2.3%.

***Table 2:*** *Number of true positives, true negatives, false negatives, and false positives for suicidal behaviors (not in parenthesis) and ideations (in parenthesis)*

| | **Predicted Behavior (Predicted Ideation)** | **Predicted No Behavior (Predicted No Ideation)** |
|---|---|---|
| **Actual Behavior (Actual Ideation)** | 40 (154) | 6 (71) |
| **Actual No Behavior (Actual No Ideation)** | 1941 (1827) | 5992 (5927) |

Discussion

This study validated performance of a published EHR-based suicide attempt risk model[21,51] for an ASD population. It is the first study to use machine learning to stratify suicide risk in an ASD population. Primary findings include the high prevalence of suicide attempt and ideation for an ASD population at VUMC. Patients with STB codes had evidence of being younger and having more visits to VUMC. There is also evidence suggesting possible "crisis" diagnosis of ASD after first suicide attempt or ideation code. Overall, the model performed quite well for the ASD population. The area under the ROC curve for the ASD population was higher than previous study validating the model for suicidal behaviors[21]. Conversely, the area under the area under the ROC curve for the ASD patients with suicidal ideations was less than the previous study[21]. The Brier scores for ideation and behavior in the ASD population much higher than the previous study[21]. Additionally, it was found that the proportion of suicidal ideation/behavior cases in the top risk quantile were much higher than the previous study with 0.69 sensitivity for suicidal ideation (compared to 0.5 in general hospital cohort[21]) and 0.87 sensitivity for suicidal behavior (compared to 0.35 in general hospital cohort[21]). There were only 6 predictions with behaviors and 71 with ideations associated that were outside of this top risk quantile. Due to the higher prevalence of suicidal ideation/behavior in the ASD cohort, the number needed to screen in the highest risk cohort was much lower than a general population with only 12 ASD patients needed to screen (compared to 23 people in general hospital cohort[21]) to have one positive prediction with suicidal ideations within the next 30 days. Similarly, only 49 ASD patients would need to be screened (compared to 271 people in general hospital cohort[21]) from the highest risk quantile to reach one positive prediction with suicidal behaviors within the next 30 days. These lower number needed to screen were obtained using a lower risk threshold than for a general population, suggesting the need for clinicians to utilize a different risk threshold for different subpopulations, in this case for patients with ASD. Utilizing this threshold would also be cost effective for both active contact and follow-up as well as cognitive behavioral therapy interventions in this cohort[53]. These results suggest that this is an adequate model for predicting suicidality in an ASD cohort.

One notable finding about the performance of this model is the relative agnosticism of the model to autistic features and ASD-specific risk factors. None of the features in the model explicitly denote patient as having "ASD". Similarly, suicidality risk factors common in autism such as "adjustment disorder"[38,50], "attention-deficit/hyperactivity disorder"[6,42], and "anxiety"[8,42,54,55] are not explicit predictors in the model. However, medications used to treat these conditions may be found in the model features. Depression is an explicit model feature that was found enriched in the predictions for the suicidal group. More research is required to learn whether ASD population is truly different in its presentation of suicidality. Such an analysis may uncover what is relevant to

predicting suicidality in an ASD population without using verbal or non-verbal clues, instead relying on the situational awareness of the patient's condition. It also may suggest that there is little need for an ASD-specific suicidality tool if this model was built on a general population. As mentioned, 4.2% of all patients at VUMC with suicidal ideations also have an ASD code, suggesting that there is already an enrichment of ASD within the suicidal population that the model was trained on.

Additionally, the most common suicide methods in this cohort were found to be drug poisonings. Previous research has indicated that generally patients with ASD do not choose this method as it is considered less lethal[50], and several studies have found people with ASD are more likely to select lethal means than the general population[6,40,50,56]. There are multiple hypotheses for why patients with ASD may generally select more lethal means, but the exact reason is unknown. The drug of choice for the most common behavior was selective serotonin reuptake inhibitors (SSRI's) which are widely used as antidepressants. These are also commonly prescribed to help treat ASD symptoms. Even though these are widely used, it is relatively unknown their effect in patients with ASD. Recent studies have shown mixed results on the effectiveness of SSRI's in the ASD population[6,10,12,35,45,54,56,57]. ASD suicidality studies have found that taking antidepressants or medications actually increased suicidality in the ASD population[6,58,59]. Further research must be conducted in this space to determine the relationship between suicidality and SSRI's in an autistic population.

Some limitations of this work include the suicidal ideation/behavior outcomes measured through ICD billing codes. One study found that "at least 75% of suicide attempts presenting to emergency department will be missed if ICD-10 codes from hospital discharge records are used"[60]. Another limitation is this was a single-center study. Patients would have to visit VUMC at least twice in the span of 30 days. They could have visited another center for suicidal ideation/behavior, and it would not be captured in our data, which may have a potential bias for only the most extreme cases of suicidality presenting to VUMC. Additionally, it was found that many patients were not formally coded or diagnosed with ASD (although there was evidence in the notes) until they presented with suicidal ideation/behaviors, suggesting there are more patients with ASD than those that would have been captured through our cohort generation. Implementation of natural language processing into the model to detect not only suicidality, but ASD features may improve model performance[61]. Another future analysis could include differentiating between patients that go on to have an ideation compared to those who proceed to have a suicidal behavior.

One major strength from this work is it utilizes real-time collection of data to stratify suicide risk. Instead, it utilizes the patient's medical history and evaluates their situation to develop a prediction score. This may be immensely helpful specifically for the ASD population due to their communication difficulties. Additionally, this work did not exclude individuals with intellectual disability, a group often left neglected in research[62,63], as 29.2% of our patient population had at least 1 ICD code of ID in their record.

## Conclusion

Although previous research has demonstrated unique risk factors of suicidality in an ASD population, an EHR-based suicide risk prediction model trained on a general population adequately performs for an ASD population. This paper identifies enriched features in the ASD population with STB codes and corroborates findings in previous studies.

# CHAPTER 2: CHARACTERIZATION OF ADULT PATIENTS WITH AUTISM SPECTRUM DISORDER THAT USE PATIENT PORTAL

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## Background and Significance

The CDC estimates that 2.2% of adults in the U.S. have autism spectrum disorder (ASD)[3], which is characterized by deficits in social communication and restricted or repetitive behaviors or activities according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition[4]. These social communication differences are often mediated through multiple co-occurring conditions associated with ASD. For example, intellectual disability (ID) affects approximately 35.2% of children with ASD (with additional 23.1% having borderline ID)[26] and individuals with ID often experience difficulties communicating[64]. These communication difficulties can extend beyond ID to include behaviors such as repetitive or rigid language, narrow interests, uneven language development, and poor nonverbal conversation skills[65] with many being diagnosed with co-occurring language disorders. One study found that 84% of children with ASD had language impairment[66]. Further compounding the communication difficulties is the fact that approximately half of persons with ASD have comorbid alexithymia, the unawareness of feelings corresponding to emotions or the inability to verbalize emotions[10]. Although current research shows that mediating alexithymia can improve mood disorders in ASD[47], persons with alexithymia have a difficult time understanding their own emotions to the point where they are unable to ask for and receive help[10,14]. In addition to the difficulties in communication, individuals with ASD often use healthcare frequently due to many other physical and mental comorbidities[17–19].

In conjunction to the communication differences and multiple co-occurring conditions in patients with ASD, patient portals are increasingly being used for managing patient care. The care provided through patient portals is recognized as a billable "e-visit" expense by the Centers for Medicare & Medicaid Services[67]. Some research suggests that patient portal messaging functions might be useful for chronic conditions like ASD[68]. Portal users are most satisfied when they have high degrees of computer control and health literacy[69]. Previous studies have shown that individuals with ASD generally have a natural affinity for technology because it is a controlled, predictable environment[70] and thus, could be a natural avenue to overcome some of the communication difficulties outlined above. Some individuals with ASD are currently using speech generating devices to help with their communication difficulties, and have been found to prefer these to picture exchange or manual sign language[71]. Additionally, one study in individuals with ID or ASD found that all participants enjoyed using the Internet for communication[72].

Currently, it is unknown how patients with ASD interact with the patient portal. Previous qualitative study showed only 1/9 mothers used the patient portal for their children with ASD[73]. This study cites multiple difficulties towards usage of the patient portal for children with ASD such as the portal not being very consumer friendly and their large number of appointments challenging the scheduling system as 5/9 mothers reported average of more than three medical appointments per week[73]. Additionally, adults with ID and developmental disabilities, such as ASD, have been underrepresented in research and funding[25,63]. In this study, we hope to characterize adult patients with ASD utilizing the patient portal to identify possible barriers to patient portal use as these are patients that are of age to make their own healthcare decisions through the patient portal.

Methods

Subjects and Data Collection

Data were collected from a major academic medical center in the mid-south, Vanderbilt University Medical Center (VUMC), using databases in EPIC Systems Clarity Database and the Vanderbilt University Research Derivative (RD)[74]. Patient portal under study is "My Health at Vanderbilt"[75] (MHAV) during the time frame of its implementation in EPIC. Patients must have had at least one visit between 1/1/2018-7/1/2022, been 18 years or older before 7/1/2022, and have two or more ICD-9-CM or ICD-10-CM codes of autism [F84.0, 299.00], Asperger syndrome [F84.5, 299.00], and/or pervasive developmental disorder not otherwise specified (PDD) [F84.9, 299.90] given on different dates or different visits. These ICD codes were selected based on the consolidation of autism, Asperger Syndrome, and PDD into ASD as specified in the newest diagnostic and statistical manual of mental disorders-5[4]. Data collected are described in **Table 3** below.

***Table 3:*** *Patient attributes*

| **Demographics** | **Zip Code attributes from uszipcode 1.0.1**[76] | **Visits** | **Co-occurring Conditions [ICD 10-CM, ICD 9-CM]** | **Portal use** |
|---|---|---|---|---|
| sex | number of housing units | number of visits | ID [(F70, F71, F72, F73, F78.*, F79)[21], (317, 318.*, 319)[22]] | days had account |
| age | number of occupied housing units | difference in time from last to first visit | Language Disorder [(F80.1, F80.2, F80.8*, F80.9, R47.9)[21], (315.3, 315.31, 315.32, 315.35, 315.39, V40.1, 784.59)[22]] | difference in days between first and last portal visits |
| ethnicity | median home value | visits per time | Depression[23] [(F32.*, F33.*, F34.1), (311.*, 296.2*, 296.3*, 300.4*)] | number of times visited portal |
| race | median household income | number of emergency department visits | Bipolar [(F30.*, F31.*)[21], (296.0*, 296.1*, 296.4*, 296.5*, 296.6*, 296.7*, 296.8*, 296.9*)[22]] | number of actions for the top 5 chart actions (else other) |
| primary language | population | number of hospital visits | Insomnia [(G47.0*, F51.0*)[21], (780.52, 327.0*)[22]] | number of portal actions by patient |
| insurance | population density | number of visits from top 10 encounter types (else other) | Anxiety [(F06.4, F41.*)[21], (300.0*, 313.0*)[22]] | number of portal actions by proxy |
| | distance to VUMC as | number of visits from top 10 | Attention-deficit/hyperactivity | |

| | | | | |
|---|---|---|---|---|
| | calculated using the Haversine distance from each patient zip code to 37232 | provider types (else other) | disorder (ADHD) [F90.*[21], 314.*[22]] | |
| | | number of visits from top 10 provider specialties (else other) | Alexithymia [R45.89, 300.89] | |
| | | number of visits from top 10 provider departments (else other) | Adjustment disorder [F43.2*[21], 309.*[22]] | |
| | | number of visits from top 10 provider department specialties (else other) | Suicidal ideation [R45.851[52], V62.84[52]] | |
| | | | Suicide attempt (see Supplementary Information, Tables S3 and S4[52] with additional ICD 10 codes of X60-X70, X84, and Y10-Y20) | |
| | | | Substance use disorder (see Appendix A, Table A.1[24]) | |

Patient message use was considered binary with one or more messages sent by patients or proxies being considered "sending messages" and no messages being sent for that patient considered "not sending messages". Proxy message use was considered if one or more messages are sent directly from a proxy account after the patient is 18 years or older. Co-occurring conditions were considered affirmative cases if patient has one or more of the Internal Classification of Diseases-Ninth or Tenth Revision-Clinical Modification (ICD-9-CM or ICD-10-CM) codes described in brackets from **Table 3** at any visit at Vanderbilt (could be outside 1/1/2018-7/1/2022 or before patient turned 18 years old) from the RD data. Patients were considered non-cases if they do not have one or more of the ICD codes for that category at any point in time using RD data. Relevant ICD codes were selected based on phecodes[77,78] and other studies conducting similar analyses based on ICD codes[52,79,80]. Zip codes were described using uszipcode 1.0.1[76] in Python. Zip codes with missing attributes were replaced by median values. This study was approved by the VUMC Institutional Review Board (#150156).

Data analysis

The ASD cohort was characterized using descriptive statistics. Outcomes were also stratified by the proportion with each comorbidity. Welch's t-tests were computed in R to determine whether there are significant differences between proportions of messengers vs non-messengers and proxy-messengers vs non-proxy-messengers amongst the co-occurring conditions. Logistic regression models for determining the odds of whether someone has sent a message and has a proxy message sent after age 18 were built in R from all data collected in **Table 3**. Both models used same 70/30

train/test split. Model performance was evaluated using area under receiver operator curve (AUROC). Odds with p<0.1 were reported.

Results

Cohort description

The 2,412 adult ASD patient cohort had 996 (41.3%) people who had sent at least one message on their account (either proxy or patient-sent) with 129 (5.3%) of patients having at least one proxy message sent after the patient was 18 years old. The cohort consisted of 1688 (70.0%) males and 724 (30.0%) females. In the cohort, 1833 (76.0%) patients were coded as white, 290 (12.0%) patients were coded as black or African American, and 223 (9.2%) patients were coded as unknown race. For insurance, 1105 (45.8%) individuals had private insurance, 791 (32.8%) have Medicaid insurance, 270 (11.2%) have other government insurance, and 156 (6.5%) have Medicare insurance. Regarding patient's primary language, 2353 (97.6%) patients' primary language is English with 38 (1.6%) patients' primary language is Spanish. Average patient age is 26.0 years old, and median patient age is 22.1 years old.

Below in **Table 4** outlines the differences between messengers vs non-messengers and proxy vs non-proxy people stratified by co-occurring conditions as heat map. "***" denotes p<0.01, "**" denotes p<0.05, and "*" denotes p<0.1.

***Table 4:*** *Differences in proportions of messengers vs non-messengers and proxy vs non-proxy people by co-occurring conditions*

| Co-occurring Conditions | Overall Prevalence | No message | Yes message | p value for message | No proxy | Yes proxy | p value for proxy |
|---|---|---|---|---|---|---|---|
| alexithymia | 2.8 | 2.5 | 3.3 | 2.3E-01 | 2.6 | 7 | 5.9E-02 * |
| adjustment disorder | 6.7 | 6 | 7.7 | 9.0E-02 * | 6.8 | 8.5 | 9.6E-01 |
| suicide attempt | 11 | 11.1 | 10.9 | 8.2E-01 | 11.1 | 15.5 | 1.0E-01 * |
| suicidal ideation | 14.2 | 14.3 | 14.1 | 8.5E-01 | 14.5 | 15.5 | 1.3E-01 |
| substance use disorder | 15.3 | 15 | 15.9 | 5.4E-01 | 15.9 | 17.8 | 6.1E-01 |
| bipolar | 19.4 | 18.3 | 21 | 9.5E-02 * | 19.9 | 26.4 | 1.1E-02 ** |
| insomnia | 20 | 15.7 | 26.2 | 2.5E-10 *** | 19.9 | 27.1 | 2.5E-03 *** |
| intellectual disability | 25.3 | 24 | 27.2 | 6.8E-02 * | 25.4 | 37.2 | 2.3E-02 ** |
| language disorders | 27.9 | 28 | 27.6 | 7.9E-01 | 26.6 | 41.1 | 2.3E-06 *** |
| depression | 30 | 24.1 | 38.5 | 1.0E-14 *** | 30 | 38.8 | 2.8E-02 ** |
| ADHD | 42.8 | 41.9 | 44 | 2.9E-01 | 41.5 | 57.4 | 2.2E-06 *** |
| anxiety | 52 | 44 | 63.8 | 6.1E-24 *** | 51.9 | 65.9 | 3.1E-05 *** |

Models

Below in **Table 5** are the factors with p<0.1 for the messenger logistic regression model and their odds. AUROC for this model was 0.92.

***Table 5:*** *Factors with p<0.1 for messenger model*

| Factors | Odds | Standard error | Pr(>\|z\|) |
|---|---|---|---|
| Number of days having My Chart | 1.9E-03 | 2.2E-04 | < 2e-16 |
| Number of My Chart Portal Actions | 9.5E-03 | 1.5E-03 | 5.0E-10 |
| Number of My Chart Visits | -3.1E-02 | 5.2E-03 | 2.3E-09 |
| Encounter Type Telemedicine Visit | 5.9E-01 | 1.3E-01 | 1.4E-05 |
| Provider Type Counselor | 8.8E-01 | 2.2E-01 | 5.6E-05 |
| Number of My Chart Inpatient Admissions | -2.2E-02 | 5.7E-03 | 8.3E-05 |
| Provider Specialty Licensed Professional Counselor | -5.7E-01 | 1.6E-01 | 4.6E-04 |
| Number of days using My Chart | -1.1E-03 | 3.9E-04 | 3.1E-03 |
| Provider Type Psychologist | -3.7E-01 | 1.3E-01 | 3.5E-03 |
| Number of portal actions by Proxy | 4.3E-03 | 1.5E-03 | 4.4E-03 |
| Provider Department Specialty Pediatric Endocrinology | 1.5E-01 | 5.7E-02 | 7.6E-03 |
| Number of visits to emergency department | -3.2E-01 | 1.3E-01 | 9.8E-03 |
| Number of My Chart Health Feed actions | 1.4E-02 | 5.9E-03 | 1.6E-02 |
| Male Patient | -5.1E-01 | 2.2E-01 | 1.8E-02 |
| Number of My Chart Messaging Actions | 1.5E-02 | 6.3E-03 | 2.1E-02 |
| Visit Density | -2.7E+00 | 1.2E+00 | 2.7E-02 |
| Encounter Type Procedure Visit | 2.2E-01 | 9.8E-02 | 2.7E-02 |
| Substance Use Disorder Comorbidity | -6.7E-01 | 3.1E-01 | 2.9E-02 |
| Encounter Type Clinical Support | 5.0E-01 | 2.5E-01 | 4.6E-02 |
| Provider Department Behavioral Health General Psychiatric Hospital | 2.2E-01 | 1.1E-01 | 5.4E-02 |
| Intellectual Disability Comorbidity | 4.6E-01 | 2.5E-01 | 6.0E-02 |
| Private Insurance | 4.4E-01 | 2.4E-01 | 6.9E-02 |
| Provider Type Resident Physician | -2.1E-01 | 1.1E-01 | 7.3E-02 |
| Provider Department Behavioral Health Pediatrics | 1.8E-01 | 1.0E-01 | 8.5E-02 |
| Zip Code Median Home Cost | 4.5E-06 | 2.7E-06 | 8.8E-02 |
| Provider Department Behavioral Health Pediatric Community Mental Health | 2.0E-01 | 1.2E-01 | 8.8E-02 |
| Language Disorder Comorbidity | 3.9E-01 | 2.3E-01 | 9.2E-02 |
| Provider Type Registered Nurse | -4.0E-01 | 2.4E-01 | 9.5E-02 |

Below in **Table 6** are the factors with p<0.1 for the proxy logistic regression model and their odds. AUROC for this model was 0.74.

***Table 6:*** *Factors with p<0.1 for proxy model*

| Factors | Odds | Standard Error | Pr(>\|z\|) |
|---|---|---|---|
| Number of days having My Chart | 2.5E-03 | 4.6E-04 | 4.7E-08 |
| Number of My Chart Portal Actions | -4.2E-03 | 9.3E-04 | 6.5E-06 |
| Number of My Chart Visits | 1.3E-02 | 3.5E-03 | 2.5E-04 |
| Number of My Chart Health Feed actions | 1.0E-02 | 3.2E-03 | 1.2E-03 |
| Number of days using My Chart | -1.7E-03 | 5.5E-04 | 1.5E-03 |
| Provider Department Specialty Radiology | 3.4E-01 | 1.2E-01 | 5.3E-03 |
| Number of My Chart Messaging Actions | 7.0E-03 | 2.6E-03 | 7.4E-03 |
| Encounter Type Office Visit | 2.1E-01 | 8.1E-02 | 8.4E-03 |
| Encounter Type Telemedicine | 2.4E-01 | 9.9E-02 | 1.7E-02 |
| Provider Type Resident Physician | -2.2E-01 | 9.3E-02 | 2.1E-02 |
| Provider Department Specialty Pediatric Radiology | 2.4E-01 | 1.1E-01 | 2.6E-02 |
| Number of My Chart Inpatient Admissions | 1.0E-02 | 4.6E-03 | 2.7E-02 |
| Provider Specialty Nurse Practitioner-Pediatrics | -3.8E-01 | 1.9E-01 | 4.0E-02 |
| Provider Department Specialty Behavioral Health | -1.5E-01 | 7.4E-02 | 4.5E-02 |
| Number of My Chart Login | -1.6E-02 | 8.3E-03 | 6.0E-02 |
| Provider Type Physician | -1.5E-01 | 8.4E-02 | 6.7E-02 |
| Zip Code Median Home Cost | 9.1E-06 | 5.1E-06 | 7.3E-02 |
| Provider Specialty Neurology | -4.0E-01 | 2.3E-01 | 7.7E-02 |
| Number of days between first and last visits | 1.2E-03 | 6.7E-04 | 8.0E-02 |
| Provider Department Pediatric Behavioral Health | 1.8E-01 | 1.0E-01 | 8.2E-02 |
| Medicare Insurance | 1.7E+00 | 9.8E-01 | 8.9E-02 |
| Provider Department Specialty Neurology | 1.7E-01 | 1.0E-01 | 9.1E-02 |

Discussion

This study explored patient portal use and factors affecting patient portal use in an adult ASD cohort. Primary findings include the high prevalence of co-occurring conditions in ASD. Anxiety (52.0%), ADHD (42.8%), depression (30%), language disorders (27.9%), and intellectual disability (25.3%) were comorbid for over 25% of the study cohort which consisted of adults. Our findings also suggest an enrichment of suicidal ideation (14.2%) and suicide attempt (11.0%) in this population compared to general population estimates across a lifetime[81]. Although this was an adult cohort, the cohort consisted of mostly male (70%) young adults (average and median age below 30 years old). Our findings indicate that patient messenger and proxy status are ascertainable targets for regression analyses (high AUROC) from EHR data.

**Table 4** suggests that individuals with comorbid adjustment disorder, bipolar, insomnia, ID, depression, and anxiety are more likely to have sent messages than not have sent messages. The message model in **Table 5** seems to suggest that telemedicine, zip codes with high home costs, and private insurance were correlated with message use and male patients, more emergency department visits, and higher visit density were associated with less messages. **Table 5** also suggests that individuals with substance use disorder are less likely to send messages and

individuals with ID are more likely to have sent messages. It was found that overall, 5.3% of adult patients with ASD have at least one proxy message sent after they turned 18 years old. **Table** suggests that individuals with alexithymia, suicide attempt, bipolar, insomnia, ID, language disorders, depression, ADHD, and anxiety are more likely to have proxy messages.

At VUMC, adults with ability to make their own medical decisions can invite another adult to delegate access or an adult who lacks the capacity to make medical decisions can have a surrogate proxy account made available to their caregivers[75]. Surrogate access has set expiration dates that must be reviewed and renewed periodically, including when patient turns 18 years old[75]. These policies ensure that individuals are not arbitrarily or easily granted proxy access. Even with this robust system for proxy access, compared to previous studies, the number of adults with proxy account message status (5.3%) seems high. One study found that 4% of messages sent from their control population were sent via proxy after manual review of messages[82]. Another study looking at patients and their proxy caregivers at the onset of serious illness and end-of-life, found 2.4% and 2.5% of patients had caregivers respectively[83]. These suggest that patients with ASD are more likely to have proxy portal use than other populations. This result in combination with the relatively low number of patients that have sent a patient portal message in this cohort, suggests that some individuals with ASD may have difficulty interacting with the patient portal on their own.

A previous study at VUMC found that 63-90% of employees used patient portal message functionality[84], whereas our study cohort had only 41.3% of patients having sent messages directly or from proxy account. As **Table** suggests, some of this difficulty in interacting with the patient portal are correlated with ID and language disorders as a high percentage of individuals with ID and language disorders have proxy messages sent after age 18. Future research should explore why individuals with these co-occurring conditions are more likely to have proxy portal use such that we can better facilitate communication for individuals with ASD through the patient portal. Previous research has shown significant differences in patient self-report and parental-proxy report of quality of life for individuals with ASD with the proxy reports often being lower than self-report[85]. This highlights the need to better facilitate patient self-report, particularly for individuals with ASD. Additionally, it should be noted that building better informatics tools to help people with ASD will also likely help support other individuals[86]. For example, some individuals with ASD already utilize augmentative and alternative communication (AAC) devices to communicate[71]. Implementation of AAC in patient portals might help not just individuals with ASD, but also others who might have difficulty in describing a complex medical phenomenon.

For both the messenger and proxy models, it was found that "Encounter Type Telemedicine" increased odds. Current research suggests that telemedicine encounters might benefit individuals with ASD. One rationale for telehealth for individuals with ASD is that some individuals do not "travel well" and telehealth allows for more "separation (physical and psychological) for more naturalistic observations"[87]. Telehealth gives patients and their caregivers more control over their environment and allows clinicians the ability to view patient in natural setting for the patient. Although telehealth may have benefits for some populations, the ability to conduct telehealth presupposes access to device, reliable internet connection, and private space for discussion[88]. Although it was outside the scope of this project to accurately estimate patient social determinants of health, it should be noted that that approximately 12% of people experiencing homelessness (PEH) have ASD[89]. One study estimated that without access to telehealth visits, 29.1% of PEH would have visited the emergency department and 38.2% would have not received care[90], which corroborates the lower odds for the messenger use models seen in **Table 5** for "Number of visits to emergency department" and "visit density" suggesting that patient is less likely to send message.

Further, the presence of "Medicare Insurance" for individuals with proxy messages in **Table** suggests that those with proxy messages are more likely to have insurance coverage because they have caregivers willing to care for them.

Some limitations of this work include cohort generation determined by ICD codes. ASD diagnostic status was not validated using Autism Diagnostic Observation Schedule[91] or other "gold standard" diagnostic tools. Additionally, this study considered an individual as having a comorbidity if there was only one ICD code at any point in time. This ensured that we had high recall, but low precision and did not consider the temporality of the comorbidity diagnosis and the message or proxy status. Another limitation is this was a single-center study. Patients need to have had two ASD ICD codes at two separate visits or two separate dates, but this did not ensure that VUMC was the patient's medical home. Lastly, we determined proxy status based on whether message was sent via a proxy account. Someone who is not the patient could login through the patient's account and communicate on behalf of the patient and this would not be designated as a proxy message because it was not through a proxy account (as it was sent through the patient's account). Future study could look at 1st vs 3rd person language use in the messages to determine whether message was sent via proxy.

## Conclusion

In conclusion, this study found that adults with ASD are less likely to use messaging functionality than other patient populations and are more likely to have a message sent via proxy than other patient populations. Comorbid mental illness was correlated with using messaging functionality. ID and language disorders were correlated with proxy message use. These findings underline the need for informatics-driven resources like patient portals to support all individuals with ASD. Future research should investigate these correlations to better understand their causal mechanisms. Individuals with ASD should be included in the development of technology to support their needs.

## SUMMARY

Individuals with ASD are at higher risk for suicide than individuals without ASD. Currently, we are not doing a particularly good job of identifying patients with autism spectrum disorder (ASD) at risk for suicide. The goal of these projects was to identify suicide risk in patients with ASD using existing automatically collected electronic health record (EHR) data with the goal of better connecting patients to needed care. We hoped to achieve this goal by validating an existing EHR-based suicide readmission model (Vanderbilt Suicide Attempt and Ideation=VSAIL) and characterizing the communication of suicidality in the My Health at Vanderbilt (MHAV) patient portal.

In chapter 1, we corroborated existing studies finding high levels of suicidal thought or behaviors (STB) in the ASD population. We also found some evidence to suggest that some patients are being diagnosed with ASD after STB, suggesting a "crisis" diagnosis of ASD. This highlights how we are currently not doing a good job of identifying individuals with ASD until there is a crisis that necessitates that they receive help. Overall, we found that VSAIL applied to ASD population outperformed VSAIL applied to a more general hospital population, suggesting that there may not be the need to develop a separate ASD-specific model for suicide risk. Importantly, using VSAIL model does not require face-to-face questioning or a social component to help prognosticate risk, something that could be especially important for individuals with ASD.

In chapter 2, we corroborated existing studies finding high prevalence of multiple co-occurring conditions in the population of individuals with ASD. Additionally, compared to other patient populations, adults with ASD are more likely to have a message sent via proxy. This suggests that adults with ASD sometimes have caregivers that assist with evaluating and managing their care. Usage of telemedicine also increased odds for both messaging and proxy use, suggesting that individuals interacting with telemedicine often are comfortable sending messages and have caregivers sending messages. We also found that individuals with co-occurring mental illness were more likely to send messages. This suggest that patient portal messages may be a useful data stream for the identification of STB in a population of individuals with ASD.

Together, these projects suggest that existing algorithms, such as VSAIL, can help accurately assess suicide risk in individuals with ASD, but that additional data, such as messages from MHAV, might be useful in the assessment of suicide risk. This would allow the patient portal to be useful in delivering care for those experiencing STB, and possibly improve access to healthcare for individuals who prefer to interact with the patient portal and telehealth platforms. Future studies might further investigate the correlations that were discovered here to better understand their causal mechanisms (if any).

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