

DELAYED OR MISSING PREVENTATIVE CARE AND
PROBLEMS GETTING SPECIALIST CARE
IN CHILDREN WITH MENTAL
HEALTH DISORDERS

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ABSTRACT

Purpose/hypothesis: The purpose of this study was to use the National Survey of Children's Health 2011/2012 (NSCH 2011/12) data set to determine if children with diagnosed mental health disorders (MHD) (depression and/or anxiety) have delayed or missed preventative healthcare services (medical, dental, vision care), and if their parents reported difficulty getting them the care they need at a different rate than children without MHD. Population of interest: Children (0-18 years of age) and their guardians who completed the survey were included in the analyses. Methods: For both hypotheses, we defined subject's exposure (having MHD) and outcome (missed or delayed care/problem getting care) based on parental response to interview questions (N = 73,632,881). Covariates adjusted for in our models included child/parent demographics, insurance status, household employment, and DHHS poverty level. Both research questions were evaluated using multi-variable logistic regression (adjusted as necessary using the correct sampling methods as suggested by the NSCH). Results: The odds of having missing or delayed care for a child with MHD were 2.24 times higher (95% CI: 1.82-2.77) than a child without MHD. The odds of the parent reporting problems getting care for a child with MHD were 2.11 times higher (95% CI: 1.74-2.60) than a child without MHD. Clinical Relevance: These findings highlight a need to focus on finding ways to promote and provide all of the healthcare that a child needs. Children with MHD have many healthcare needs that other children may not, but they still need adequate preventative care. This may bring the specific needs of a population needing extra help to the attention of healthcare providers and outreach programs.

To my parents: Jules and Bea,
and to Katie. Thank you
for your unending support.

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CHAPTER 1

INTRODUCTION

Children are in a vulnerable position and need to rely on their caregivers to schedule and transport them to their well and emergent healthcare visits. Children with mental health disorders (MHD) have an immediate, on-going need to receive mental healthcare in addition to the standard preventative care services that are needed for all children. In the wake of needing numerous healthcare visits, it is possible that children with diagnosed MHD may receive less than optimal preventative care, given the numerous mental health visits these children require. The purpose of the proposed study is to use the National Survey of Children's Health 2011/2012 (NSCH 2011/12) data set to determine if children with diagnosed MHD (depression and/or anxiety) have delayed or reduced preventative healthcare services (medical, dental, vision care) more often than children without MHD, or if they reported more difficulty getting the care they need. Confounders of interest include family socioeconomic status, household demographics, and the child's insurance status, as they heavily influence a guardian's healthcare seeking for the child (Abbas, S. et al, 2016; Janicke, D. M. et al, 2001).

The relationship between MHD and healthcare service utilization is well studied in adults and certain subsets of populations of children, but the conclusions of these studies are not always in agreement. There are bodies of evidence showing that those with MHD use preventive healthcare services more often in certain subsets of populations, but there is also evidence of the opposite in other populations. Many of these studies focus on highly specific subsets of populations, and the results are not very generalizable. The relationship between MHD and preventive healthcare service

utilization in adults may give us some key insights into the same relationship in children, but there are some factors for care utilization that are unique to children. Children rely on their caregivers to schedule and transport them to all of their healthcare appointments.

If children with MHD receive less preventative healthcare than children without MHD, this finding would highlight the need to identify ways for those children to access the care that they need. The needs of children with MHD are great and parents of children with MHD have numerous demands, but finding ways to promote and provide all of the healthcare that a child needs is key to raising a healthy child.

Ensuring that individuals, children especially, get the preventive healthcare that they require is extraordinarily important. A study conducted by Weitkamp et al concluded that children aged 6 to 18 years with MHD report a much lower health related quality of life than those without MHD even when controlling for other co-morbid factors. Other factors associated with quality of life were found to be gender, age, functional impairment, and family function (Weitkamp, K., et al 2013). Therefore, improving the access and utilization of preventive healthcare in those individuals with MHD should be a priority.

To our knowledge, whether reduced utilization is occurring for all preventive healthcare visits (medical, dental, vision) has not been determined among children with MHD. In children with diagnosed mental disorders, mothers may perceive their child's mental health issues to be more important than other preventive services, making them less of a priority. This study will add to existing knowledge by using a large, de-identified national dataset (NSCH 2011/12) to assess that relationship.

CHAPTER 2

REVIEW OF LITERATURE

Research on primary care utilization among children with MHD is severely lacking, and while adult and child populations have differing mechanisms by which they access preventive care, research studying the association between adult mental health and primary care utilization will be used to give insight into potential cofactors that may influence care utilization. Some studies exploring the relationship between MHD and primary care utilization among adults have found that those with MHD utilize primary care less often than those individuals without MHD. A study published in 2013 by David Scott and Brenda Happell assessed the relationship between utilization of primary healthcare, the perception of the quality of that care, and mental illness in Australia. Individuals with MHD reported more problems accessing care and had odds ranging from 1.54 to 1.71 times higher (95% CI: 1.15-2.06; 1.28-2.28, respectively) of not utilizing healthcare services in the past 12 months compared to others (Scott, D. & Happell, B., 2013). Another study conducted on Veteran's Affairs primary care use found that veterans with depression had an 11% lower rate of primary care utilization than individuals with either post-traumatic stress disorder or substance abuse disorder (Davis, T.D. et al, 2014).

While there are studies showing there is decreased primary care use in individuals with MHD, there are others that show the opposite relationship. These studies, however, have been conducted on different populations with different co-morbid factors, and this relationship has not been examined in adolescent populations. A systematic review of the association between depression and healthcare utilization in children and adults with

sickle cell disease identified 12 studies with a total of 50,036 individuals. Seven of the twelve studies reviewed found a statistically significant relationship between depression and healthcare utilization. For those studies that found a significant relationship, risk of being a high utilizer of healthcare services ranged from 2-8 times greater relative risk for depressed individuals compared to non-depressed individuals. Most of the studies included in the review were retrospective in design and looked at emergency department visits and hospitalizations over a course of a year. Carroll et al had 2 studies included in the review that had a significant relationship from the years 2011 and 2013. In 2011 they found a 6.80 times greater risk (95% CI: 4.26-10.84) of visiting the ED in patients with depression. In 2013 they found a 1.65 times greater risk (95% CI: 1.04-2.61). Those with depression often had poorer health outcomes than those without depression, and this, in turn, may have affected the relationship between depression and healthcare utilization. Studies included in the review were also relatively small in sample size and retrospective in design, so more research may be needed on a larger scale or of a prospective design in order to build more scientific evidence (Jonassaint, C.R., et al, 2016). Another study by Luber, et al (2001) examining the relationship between depression and healthcare utilization of 3,481 elderly patients seen in a primary care practice in the last 12 months found patients with depression had an increased outpatient service utilization (6.3 visits for depressed patients vs 3.9 visits for non-depressed patients; $P < 0.001$) (Luber, M.P. 2001). None of this research, however, focused solely on preventive care or preventive care in adolescents. Emergency care and hospitalizations do not have the same focus on early detection and prevention as a primary care visit would, however examining factors

that contribute to the type of care an individual with MHD uses is useful for building an understanding of their use of the entire healthcare service line.

While there is no research published specifically involving individuals with MHD and their utilization of vision care, there is some research describing the general factors associated with vision care utilization. A study of 11,015 Canadian adolescents (aged 12 to 17 years) who participated in the Canadian Community Health Survey in 2007-2008 found that government sponsored vision care insurance (OR = 0.08; 95% CI: 0.67-0.85), being male (OR = 0.90; 95% CI: 0.84-0.97), their parents not owning the home they lived in (OR = 0.91; 95% CI: 0.72-0.92), reading fewer than 3 hours weekly (OR = 0.87; 95% CI: 0.81-0.94), and being non-diabetic (OR = 1.67; 95% CI: 1.29-2.15) were all associated with not utilizing vision care (Xu, K., et al, 2012). A study of 152 adults in a low-income multi-ethnic population conducted in Las Angeles County, California found that 25% of respondents reported never having been told by their primary care provider that they needed an eye exam (OR = 3.9; $p < 0.01$). Lack of vision insurance (OR = 3.2; $p < 0.01$), and lack of a primary care provider (OR = 2.4; $p < 0.01$) were also associated with not utilizing vision care (Baker, R.S., et al, 2005). As with adults, if parents aren't told by their child's primary care provider that they need to take them for an eye exam, or if they don't utilize preventive healthcare at all, they may not take their child for their vision care. While the relationship between a child's mental health and their access to vision care is un-studied, it is nevertheless important and necessary that all children routinely receive the appropriate vision care and eye exams.

Using the Taiwan National Health Insurance Research Dataset for 2009, Teng et al demonstrated that children with severe MHD received dental care less often than

children without MHD; “Only 40% of 19,609 patients with severe mental illness visited the dentist within 12 months. This was significantly lower than the dental visit rate of 48.3 % for those individuals without MHD (OR = 0.72; 95% CI = 0.69-0.74)” (Teng, P. R. et al, 2016). This poor utilization of preventive dental healthcare services highlights the increased need to help those with MHD get the care that they need to reduce the risk of long-term adverse events. This is especially the case in children, as shown in an article published using the NSCH 2011/12. The study found that children who had unmet dental needs had a higher mean number of days of school missed in the past year due to injury/illness than those who did not have unmet dental needs (Agaku, I. T., et al, 2015).

Aside from the child’s MHD, there are a variety of other factors that have been shown to be associated with the utilization of preventive healthcare. A study of 87 primary care providers investigated the relationship between maternal and family mental health, poverty, and pediatric service. They found that the child’s age and race, and the family’s poverty level were associated with utilization of care. The mother’s self-report of her own mental stress was not found to significantly impact the amount of service the mother utilized but, the interaction between mental stress and self-efficacy was highly associated with high service use. This study, however, did not differentiate between types of care received; “high service users” included both preventive and acute visits (Janicke, D.M., 2003). Another study comparing maternal depression and pediatric healthcare use of 5,565 families found that children of mothers with depressive symptoms had increased use of acute care (OR = 1.44; 95% CI: 1.17-1.76) and decreased use of preventive care (OR = 0.80; 95% CI: 0.67-0.95) (Minkovitz, C.S., 2005). One study using NSCH 2011/2012 examined the geographic, racial, ethnic, and sociodemographic factors

associated with “Family-Centered” healthcare utilization of children aged 0-17 years. The study found that non-Hispanic Black and Hispanic children had “2.11 and 1.58 times higher odds, respectively, of not receiving family centered care than non-Hispanic White children” (Azuine, R.E., et al, 2015). In addition to this, the study found that those in non-English speaking homes, living in low-education or low-income households, or were uninsured had a higher chance of not receiving family centered care (Azuine, R.E., et al, 2015). Even with the trend in the US toward more equal healthcare opportunities for all, there continues to persist a discrepancy between certain groups in the utilization of care. If children with MHD are found to have more missed/delayed preventive care or more problems getting care, being a part of these groups who utilize care less often will only further the divide that exists.

Another study using the NSCH 2011/12 dataset focused specifically on the healthcare utilization of children with Autism Spectrum Disorder (ASD). The study found that privately insured children are significantly less likely to receive therapy for their ASD than their publicly insured counterparts (OR = 0.49; 95% CI: 0.30-0.79). This is due to the additional costs of therapy that are not covered in many private insurance plans. As a result, parents of children with ASD are forced to pay for therapy out of pocket if they want their child to receive these services (Zhang, W., & Baranek, G., 2016). Similar to children with diagnosed MHD (the focus of this study), children with ASD are a sub-group of children with special healthcare needs. These special needs often have barriers and limitations that are unique to the disorder and as such, it is important to look at how individuals utilize the healthcare system in an attempt to understand what influences utilization and decisions to utilize healthcare.

To date, the NSCH 2011/12 has only been used to examine mental health issues/disorders and childhood development outcomes. A 2013 study by Singh et al found that children who were born premature (< 37 weeks gestation at delivery) or of a low birth weight (<2500 grams at birth) are at statistically significantly higher risk for mental health issues/disorders than those not born either premature or at a low birth weight (Singh, G.K., et al, 2013). Using only Florida data on children 6-17 years from the NSCH 2011/12, it was found that children who lived with a parent who had poor emotional health were more likely to have anxiety or mood disorders than children who lived with a parent who had good emotional health (OR = 5.01; 95% CI: 1.89-13.29). Children who lived with a parent who had poor emotional health were also more likely to be exposed to adverse childhood experiences (ACEs) and to have unemployed parents than children with parents who had good emotional health (Reid, K.M., 2014). A study using only 2-8 year old children in the NSCH 2011/12 explored the prevalence of mental and developmental disorders and their associated factors. The study found difficulty getting by on their income, child care problems, and lacking a medical home to be most strongly associated with the child having mental and/or development disorders (Bitsko, R.H., et al, 2016). These studies may point to potential co-factors or confounding relationships that may exist in the association between child MHD and their utilization of preventive healthcare services.

A study published in 2015, focusing on children aged 6-17 explored child well-being and how it is influenced by exposure to ACEs and having a medical home, found that children with even a single adverse childhood experience had a statistically significant lower overall well-being. This relationship continued even when controlling

for age, gender, race, ethnicity, parental education, health conditions, and medical home access. The study also found that children with access to a medical home had better overall well-being than those who did not (Balistreri, K.S., 2015). Another study using the NSCH 2011/12 dataset, but focusing on children 0-17 years of age found that children with even a single ACE were more likely than children with none to have at least one physical, mental, or developmental condition (OR = 1.28; 95% CI: 1.16-1.40) This trend continued for children who have been exposed to 2 and 3+ ACEs (Bright, M.A., et al, 2015). These studies highlight association between ACEs and child health, which points to a need for screening children and referring their parents to services they may need.

However, there is evidence to suggest that ACEs and child MHD co-occur or are collinearly associated with each other. A retrospective cohort of 9,460 individuals found that current and future development of depressive disorders was collinear with having exposure to ACEs (one of which includes growing up in a household with an individual with a mental illness) (Chapman, D. et al 2003). Mental illness of another household member (including the mother) has also been found to frequently co-occur with other ACEs such as domestic violence and sexual abuse (Lu & Mueser & Rosenberg & Jankowski, 2008). While ACEs and maternal mental illness are very important and may impact a child's preventive service use, this collinearity may have a confounding effect on the present study.

CHAPTER 3

METHODOLOGY

NSCH Survey Design

The current study will use the publicly available, de-identified NSCH 2011/12, which was conducted by the CDC's National Center for Health Statistics between 2/28/11 and 6/25/2012 and was designed to assess the well-being of children aged 0-17 and their families. The 2011/12 survey was collected via cross-sectional phone interview of households with at least 1 individual aged 0-17 years in which parents, family, and household residents (who reported knowledge of the health and healthcare of the sample child) answered questions about the child's and their own health. Household demographics were collected, and the family was screened for survey eligibility. If there was a child under 18 living in the house, the survey was completed. The interviewer selected a "sample child" (S.C.) who is either the sole child in the house (under 18), or a randomly selected child if there was more than one child. From there, the study questions were directed at the "sample child", not all of the children in the house ("National Survey of Children's Health", 2016).

The sampling design used by the NSCH is the State and Local Area Integrated Telephone Survey (SLAITS), a form of random digit dialing (RDD) developed by the National Center for Health Statistics of the CDC. SLAITS is designed to provide in depth data on both a state and local area level. List-assisted RDD was used to sample landline telephones, which was supplemented with an independent RDD sample of cell-phones. Survey stratification was done by state and phone line type (landline or cell-phone number). The NSCH contracts the data collection to National Opinion Research Center at

the University of Chicago. Strict privacy regulations, in accordance with federal law upheld by the Fifth Circuit Court of Appeals, are followed in the data collection, storage, and use of the NSCH (“National Survey of Children's Health”, 2016).

The NSCH2011/2012 survey has sampling strata and weighting. This was the same sampling frame as the National Immunization Survey (NIS) conducted by the CDC, and was carried out directly following the NIS in sampled houses. Weighting was calculated beginning with the base sampling weight being set to the inverse probability of the phone number being selected. Certain adjustments were made to the base weights of the land line and cell phone strata independently prior to their being combined. These adjustments included derivation of annual sampling weight, adjustment for non-resolution of released telephone numbers, incomplete cell phone-only/main screener, incomplete age-eligibility screener, subsampling of children within household, nonresponse to NSCH interview, multiple cell phone lines, trimming of extreme weights, adjustment for combined landline and cell phone sample and non-covered children, and ranking adjustment of child weights. Population control totals used for the weighting used data from the 2011 American Community Survey. After weighting, the data estimates are representative of all non-institutionalized children 0-17 years old in the US (“National Survey of Children's Health”, 2016).

Eligibility for the survey included screening for residential status and presence of children living in the house who were 0-17 years of age at the time of the call. For the sample in the first calendar quarter of 2011, households contacted by cell-phone were only eligible if they did not have a landline in the house or respondents reported that they were unlikely to respond to landline calls. The second calendar quarter of 2011 and after

used a ‘take all’ approach to cell phone numbers, and the landline use screen was no longer used. After the eligibility screen, a single child was randomly selected to be the subject of the interview survey if there was more than one child. If there was only a single child, they were automatically selected to be the sample child (“National Survey of Children’s Health”, 2016).

Overall, 847,881 households in the 50 states and Washington D.C. were screened, with 187,422 reporting eligibility, and 95,677 completed interviews (31,972 of which were cell-phone interviews). In addition to this, 13,494 households were screened in the US Virgin Islands via landline only. 3,424 of those individuals screened reported eligibility, and interviews were completed for 2,342. Data from the US Virgin Islands survey was not, however, included in the data files released and as such is not included in this study. National response rate was 38.2% for the landline sample, and 15.5% for the cell-phone sample (23.0% combined for the dual-frame sample), with a completion rate of 54.1% for landlines and 41.2% for cell-phones. Sampling weights were adjusted to account for non-response bias (“National Survey of Children’s Health”, 2016).

The NSCH is funded by the U.S. Department of Health and Human Services, the Health Resources and Services Administration, and the Maternal and Child Health Bureau, and is conducted by the U.S. Census Bureau. This study collects myriad child health and healthcare factors including child and family demographics, child health status, child development status, insurance coverage, preventative and specialty care use, family health and activities, parental health, and neighborhood characteristics. Data are randomly sampled from all residential addresses in the United States, and released data is stripped of all identifying factors (“National Survey of Children's Health”, 2016).

Study Design

The population of interest for this study is children (0-18 years of age) and their guardians who completed the 2011/2012 NSCH survey. The study (conceptually outlined in Figure 1) will determine the association between child diagnosed MHD and the occurrence of missed/delayed preventative care and parental report of problems getting specialist care (orange arrows) while controlling for parent, child, and household demographics (black arrows). In all analyses, complex survey design including weight, and strata (state and phone line type) were taken into account.

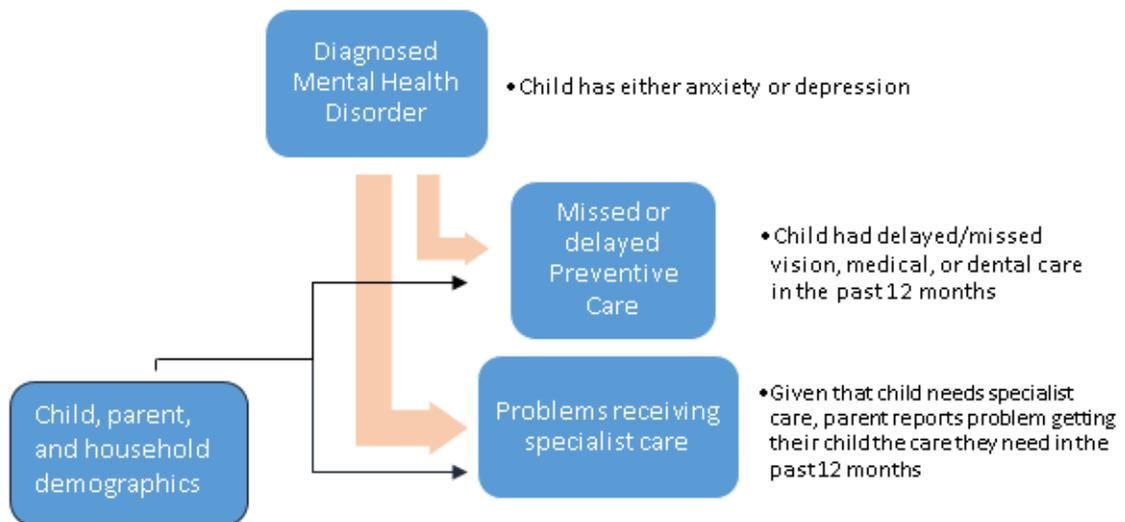


Figure 1. Conceptual model

Children who have missing data, the mother didn't know the answer, or the mother refused to answer the question for the exposures (has a doctor or other healthcare provider ever told you that (S.C.) has depression or anxiety even if they do not have the condition now) or outcomes (During the past 12 months/Since his/her birth, was there any time when (S.C.) needed healthcare but it was delayed or not received? + What type of care was delayed or not received AND During the past 12 months/Since his/her birth, how much of a problem, if any, was it to get the care from the specialists that (S.C.)

needed?) will be excluded from the analysis. All non-excluded cases will be included in the analysis.

The independent variable is a child with diagnosed MHD (Y/N), and will be defined using the question “Has a doctor or other healthcare provider ever told you that (S.C.) has depression or anxiety even if they do not have the condition now?”. Those parents who answered yes will be considered to have the exposure, and those who answer no will be considered to not have the exposure.

The dependent variable for the first outcome is delayed or non-received preventative care and will be defined using a combination of the questions “During the past 12 months/Since his/her birth, was there any time when (S.C.) needed healthcare but it was delayed or not received?” and “What type of care was delayed or not received?”. Those who answered yes to delayed/not received care and reported that that delay was “medical”, “dental”, or “vision” care will be considered to have a positive outcome.

The dependent variable for the second outcome of problems getting care will be defined as the answer to “During the past 12 months/Since his/her birth, how much of a problem, if any, was it to get the care from the specialists that needed?”. The outcome will be compressed into two classes (down from 3 possible answers): Big problem and small problem will be combined into “Positive for problem”, and the other choice “not a problem”. This is done due to the heavily skewed response rate to the question in which an inadequate number of individuals reporting that they had a “big problem”.

Covariates in the model will include child/parent demographics, insurance status, and mother’s education. ACEs (including maternal MHD) will not be included as covariates in the study as they have been found to co-occur with child MHD and would

potentially distort the true relationship if included in the model (Bright, M.A., et al, 2015; Hammen, Burge, & Adrian, 1991; Chapman, D. et al 2003; Lu, W. et al, 2008).

Statistical and Analytical Plan

All analyses will be adjusted as necessary using the correct sampling methods as suggested by the NSCH. Summary data of relevant variables (dependent variable: care delayed/not received, how much of a problem was it to get care; independent variable: MHD; cofactors: child/parent demographics, insurance status, mother education, child's primary care giver) includes N/percent for categorical variables and mean/standard deviation for continuous variables. Univariate and multivariable analysis with logistic regression models will be used to determine the relationships between child mental health status and preventative healthcare utilization. It was decided a priori that race, age, and gender for the mother and child would be included in the final analysis as well as any cofactor with a univariate p-value less than or equal to 0.20. Final conclusions for both research questions will be addressed by using multivariable logistic regression with a significance level of 0.05. All analyses were conducted in R 3.1.3 (R Core Team, 2013).

CHAPTER 4

RESULTS

Distribution of study population characteristics both in total and broken down by presence/absence of MHD are shown in Table 1. Relatively few children have MHD in the population (6.7%). The overall rate of missed/delayed care is also relatively low for the population (5.7%). This is similar to the rate for children without MHD (5.5%), but it is over double that for children with one (12.8%). Problems getting care is a much more prevalent factor than missed/delayed care, occurring in 23.5% of the total study population. That rate is, as with missed/delayed care, similar in those children without MHD (22.1%), but higher in those with one (36.2%).

Child sex is relatively evenly split and similar for those with and without MHD. The population race is 66.2% White, 14.6% Black, and 18.2% other race, though there is a higher concentration of White children with MHD (73.0%) than White children without (65.7%). Almost a quarter of the population is of Hispanic ethnicity (23.57%), but that rate is lower in children with MHD (16.9%) than those without (23.53%). The prevalence of a child lacking health insurance is low (5.5%) and similar in children with and without MHD (4.7% vs 5.8%). Mean child age is 8.6 years overall, but is higher in children with MHD (12.4 years) compared to those without (9.4 years). Mean maternal age is 37.2 years, and only slightly higher in children with MHD (40.8 years) compared to those without (38.0 years). 14.5% of mothers in the total sample had less than high school education, 20.7% had a high school degree, and 64.7% had higher than high school education. This was similar in children with and without MHD. Household employment rates showed a 15.8% unemployment rate in the total population, with similar rate in

households with children with no MHD (15.1%), but higher rates in households with children with MHD (23.6%). The highest concentrations of individual household poverty levels were located at the two extremes. 21.8% of the population is at or below 100% of the federal poverty level, but this rate was 5% higher for households with a child with MHD. 27.5% of the population is above 400% of the federal poverty level, with similar rates for those with and without MHD.

Table 1. Distribution of characteristics (N = 73,632,881)

Variable	Total	Child with MHD	Child with no MHD
Mental Health Disorder, N(%)			
Yes	4,409,587 (6.73%)	NA	NA
No	61,075,283 (93.27%)	NA	NA
Delayed/Missed, N(%)			
Yes	4,212,376 (5.73%)	562,746 (12.77%)	3,356,737 (5.51%)
No	69,346,628 (94.27%)	3,843,902 (87.23%)	57,577,132 (94.49%)
Problems Getting Care, N(%)	N=19926859		
Yes	4,693,535 (23.55%)	783,625 (36.24%)	3,471,771 (22.14%)
No	15,233,324 (76.45%)	1,378,557 (63.76%)	12,209,553 (77.86%)
Child Sex, N(%)			
Male	37,664,923 (51.15%)	2,446,669 (55.50%)	31,057,315 (50.92%)
Female	35,967,958 (48.85%)	1,961,482 (44.50%)	29,940,830 (49.08%)
Child Race, N(%)			
White	47,151,210 (66.21%)	3,159,329 (72.97%)	38,713,351 (65.67%)
Black	10,405,009 (14.61%)	490,960 (11.34%)	8,851,852 (15.02%)
Other	13,660,128 (19.18%)	679,461 (15.69%)	11,382,969 (19.31%)
Child Ethnicity, N(%)			
Hispanic	16,967,102 (23.57%)	733,330 (16.88%)	14,023,056 (23.53%)
Non-Hispanic	55,017,436 (76.43%)	3,611,063 (83.12%)	45,574,164 (76.47%)
Child Insurance Status, N(%)			
No	4,044,605 (5.50%)	205,418 (4.66%)	3,541,163 (5.81%)
Yes	69,517,476 (94.50%)	4,201,488 (95.34%)	57,392,776 (94.19%)
Child Age, Mean(SE)	8.59 (0.038)	12.35 (0.100)	9.41 (0.037)
Mother Age, Mean(SE)	37.18 (0.060)	40.80 (0.230)	38.00 (.064)
Mother Education, N(%)			
Less than High School	9,619,035 (14.54%)	486,645 (12.46%)	8,008,363 (14.46%)
High School Graduate	13,707,356 (20.72%)	838,315 (21.46%)	12,065,206 (21.78%)
More than High School	42,826,205 (64.74%)	2,582,021 (66.09%)	35,327,203 (63.77%)
Anyone in household employed?, N(%)			
Yes	60,462,603 (84.24%)	3,301,209 (76.41%)	50,473,256 (84.92%)
No	11,315,145 (15.76%)	1,019,263 (23.59%)	8,959,550 (15.08%)
Poverty level of this household based on DHHS poverty guidelines, N(%)			
<=100%	14,505,354 (21.78%)	1,091,854 (26.57%)	11,518,554 (20.90%)
(100% - 133%]	6,468,591 (9.71%)	442,012 (10.76%)	5,365,718 (9.74%)
(133% - 150%]	1,281,216 (1.92%)	85,419 (2.08%)	1,048,780 (1.90%)
(150% - 185%]	4,978,242 (7.48%)	345,724 (8.41%)	4,070,793 (7.39%)
(185% - 200%]	1,923,781 (2.89%)	100,244 (2.44%)	1,626,010 (2.95%)
(200% - 300%]	11,025,465 (16.56%)	594,596 (14.47%)	9,288,497 (16.86%)
(300% - 400%]	8,101,582 (12.17%)	445,727 (10.85%)	6,865,598 (12.46%)
>400%	18,303,713 (27.49%)	100,3225 (24.42%)	1,5316,560 (27.80%)

All missing data <1% of total N, except for "Problem Getting Care" as it is a subset of data

Factors considered in univariate analysis for the first research question are shown in Table 2. For this outcome, all univariate associations fit the criteria to be included in the final analysis. Multivariable logistic regression (Table 3) showed that MHD, Black race, being un-insured, older age of the child, higher education level achieved by the mother, and greater level of poverty were associated with missed/delayed care for the child in the past 12 months. When controlling for other variables in the model, children with MHD were significantly more likely to miss care (OR = 2.24; 95% CI: 1.81-2.77).

The odds of missing care for Black children, insured children, each year increase in the child's age, those whose mother was a high school graduate, those whose mother had more than high school education, households 200-300% federal poverty line, households 300-400% of the federal poverty line, and households at or above 400% of the poverty line were 1.36, 0.226, 1.05, 1.44, 1.78, 0.67, 0.44, and 0.231 respectively as compared to their reference categories (Corresponding 95% CIs are: 1.11-1.67, 0.18-0.28, 1.03-1.07, 1.09-1.92, 1.30-2.43, 0.52-0.88, 0.32-0.61, and 0.18-0.31). Child sex, 'other' race, Hispanic ethnicity, mother age, household employment, and being below 200% of the federal poverty line were not significantly associated with missed/delayed care.

Table 2. Factors independently associated with missed/delayed care by univariate logistic regression

Variable	Not		Crude Odds		
	Missed/Delayed	Missed/Delayed	Ratio	95% CI	p-value
Mental Health Disorder	N = 391,893		N = 61,614,637		
Yes	562,746 (14.35%)	3,846,677 (6.24%)	2.511	2.107-2.992	<0.001*
No	3,359,147 (85.65%)	57,767,960 (93.76%)	Ref	Ref	Ref
Child Sex					
Male	2,185,224 (52.01%)	35,479,130 (51.10%)	Ref	Ref	Ref
Female	2,016,578 (47.99%)	33,948,877 (48.90%)	0.999	0.874-1.140	0.983
Child Race					
White	2,375,996 (57.91%)	44,774,043 (66.72%)	Ref	Ref	Ref
Black	854,538 (20.83%)	9,550,419 (14.23%)	1.672	1.397-2.001	<0.001*
Other	872,529 (21.27%)	12,787,599 (19.05%)	1.364	1.138-1.635	<0.001*
Child Ethnicity					
Hispanic	1,032,462 (24.87%)	15,933,962 (23.49%)	1.127	0.939-1.353	0.201*
Non-Hispanic	3,118,566 (75.13%)	51,898,324 (76.51%)	Ref	Ref	Ref
Child Insurance Status					
Yes	3,205,747 (79.26%)	66,149,085 (95.38%)	0.193	0.159-0.236	<0.001*
No	838,858 (20.74%)	3,205,747 (4.62%)	Ref	Ref	Ref
Child Age	9.647 (0.170)	8.530 (0.039)	1.027	1.011-1.043	0.000795*
Mother Age	42.920 (1.639)	47.736 (0.808)	0.993	0.984-1.002	0.113
Mother Education					
Less than High School	586,714 (15.23%)	9,032,321 (14.29%)	Ref	Ref	Ref
High School Graduate	997,005 (25.88%)	13,710,187 (21.70%)	1.119	0.878-1.426	0.363
More than High School	2,269,261 (58.90%)	40,445,025 (64.10%)	0.833	0.667-1.041	0.108
Anyone in household employed?					
Yes	3,284,573 (79.24%)	57,176,806 (84.54%)	0.720	0.612-0.847	<0.001*
No	860,577 (20.76%)	10,454,567 (15.46%)	Ref	Ref	Ref
Poverty level of this household based on DHHS poverty guidelines					
<=100%	1,198,086 (30.23%)	13,307,104 (21.25%)	Ref	Ref	Ref
(100% - 133%]	639,920 (16.15%)	5,826,823 (9.30%)	1.217	0.961-1.541	0.1027*
(133% - 150%]	126,288 (3.19%)	1,154,927 (1.84%)	1.246	0.789-1.965	0.346
(150% - 185%]	410,821 (10.37%)	4,567,421 (7.29%)	1.033	0.803-1.330	0.800
(185% - 200%]	146,525 (3.70%)	1,777,256 (2.84%)	0.880	0.604-1.284	0.508
(200% - 300%]	678,880 (17.13%)	10,346,477 (16.52%)	0.744	0.604-0.917	0.0055*
(300% - 400%]	345,849 (8.73%)	7,755,544 (12.38%)	0.475	0.359-0.630	<0.001*
>400%	416,969 (10.52%)	17,886,123 (28.56%)	0.245	0.200-0.300	<0.001*

Table 3. Factors independently associated with missed/delayed care by multivariable logistic regression

Variable	Adjusted Odds		
	Ratio	95% CI	p-value
Mental Health Disorder (Reference is No)			
Yes	2.244	1.819-2.768	<0.001*
Child Sex (Reference is Male)			
Female	1.023	0.885-1.1829	0.754
Child Race (Reference is White)			
Black	1.363	1.112-1.671	0.003*
Other	1.166	0.952-1.428	0.138
Child Ethnicity (Reference is Non-Hispanic)			
Hispanic	0.877	0.693-1.110	0.275
Child Insurance Status (Reference is No)			
Yes	0.226	0.181-0.282	<0.001*
Child Age	1.048	1.025-1.072	<0.001*
Mother Age	0.999	0.986-1.0109	0.821
Mother Education (Reference is Less than HS)			
High School Graduate	1.443	1.086-1.917	0.011*
More than High School	1.776	1.298-2.430	<0.001*
Anyone in household employed? (Reference is No)			
Yes	0.956	0.783-1.166	0.655
Poverty level of this household based on DHHS poverty guidelines (Reference is <=100%)			
(100% - 133%]	1.085	0.839-1.402	0.535
(133% - 150%]	1.239	0.744-2.063	0.410
(150% - 185%]	0.931	0.695-1.248	0.634
(185% - 200%]	0.824	0.557-1.219	0.333
(200% - 300%]	0.674	0.518-0.877	0.003*
(300% - 400%]	0.441	0.317-0.613	<0.001*
>400%	0.231	0.176-0.305	<0.001*

Factors considered in univariate analysis for the second research question are shown in Table 4. For this outcome, all univariate associations fit the criteria to be included in the final analysis. Multivariable logistic regression (Table 5) showed that MHD, race, being uninsured, younger age of mother, education level, and percent federal poverty level were associated with problems getting needed specialist care for the child in the past 12 months. When controlling for other variables in the model, the odds of reporting problems getting care were significantly higher when the child had MHD (OR = 2.11; 95% CI: 1.71-2.60).

The odds of reporting problems getting care for Black children, 'other' race children, insured children, each year increase in the mother's age, those whose mother was a high school graduate, households 100-133% of the federal poverty line, households at 200-300% federal poverty line, and households at >400% federal poverty line were 1.60, 1.50, 0.37, 0.99, 0.66, 1.35, 0.72, and 0.53 respectively as compared to their reference categories (Corresponding 95% CIs: 1.29-1.98, 1.19-1.89, 0.26-0.54, 0.98-0.99, 0.48-0.90, 1.01-1.81, 0.55-0.93, and 0.41-0.69). Child sex, Hispanic ethnicity, child age, mother with more than highschool education, household employment, and being 133-200% or 300-400% federal poverty line were not associated with problems getting care.

Table 4. Factors independently associated with problems getting care by univariate logistic regression

Variable			Crude Odds		
	Problem	No Problem	Ratio	95% CI	p-value
Mental Health Disorder	N = 4,692,643	N = 1,533,082			
Yes	783,625 (18.39%)	1,384,575 (10.11%)	1.999	1.670-2.393	<0.001*
No	3,478,100 (81.61%)	12,310,945 (89.89%)	Ref	Ref	Ref
Child Sex					
Male	2,532,091 (53.96%)	8,224,802 (53.65%)	Ref	Ref	Ref
Female	2,160,552 (46.04%)	7,105,580 (46.35%)	0.981	0.859-1.121	0.781
Child Race					
White	2,717,417 (59.57%)	10,954,243 (73.10%)	Ref	Ref	Ref
Black	781,656 (17.13%)	1,734,440 (11.57%)	1.836	1.526-2.210	<0.001*
Other	1,062,768 (23.30%)	2,297,410 (15.33%)	1.912	1.585-2.307	<0.001*
Child Ethnicity					
Hispanic	1,216,604 (26.28%)	2,714,485 (18.02%)	1.677	1.388-2.027	<0.001*
Non-Hispanic	3,412,970 (73.72%)	12,348,863 (81.98%)	Ref	Ref	Ref
Child Insurance Status					
Yes	4,366,785 (93.08%)	15,018,655 (97.95%)	0.256	0.181-0.360	<0.001*
No	324,627 (6.92%)	313,878 (2.05%)	Ref	Ref	Ref
Child Age	9.209 (0.159)	9.163 (0.079)	0.986	0.971-1.000	0.0555*
Mother Age	50.200 (3.362)	47.503 (1.490)	0.973	0.964-0.981	<0.001*
Mother Education					
Less than High School	686,716 (15.85%)	1,179,545 (8.28%)	Ref	Ref	Ref
High School Graduate	912,763 (21.06%)	2,544,148 (17.86%)	0.518	0.387-0.693	<0.001*
More than High School	2,734,064 (63.09%)	10,517,623 (73.85%)	0.398	0.307-0.516	<0.001*
Anyone in household employed?					
Yes	3,648,788 (78.96%)	13,081,454 (86.94%)	0.583	0.483-0.704	<0.001*
No	971,987 (21.04%)	1,965,182 (13.06%)	Ref	Ref	Ref
Poverty level of this household based on DHHS poverty guidelines					
<=100%	1,108,536 (25.73%)	2,251,782 (16.04%)	Ref	Ref	Ref
(100% - 133%]	608,765 (14.13%)	1,034,464 (7.37%)	1.127	0.858-1.482	0.391
(133% - 150%]	73,104 (1.70%)	209,748 (1.49%)	0.629	0.398-0.993	0.04672*
(150% - 185%]	408,997 (9.49%)	932,269 (6.64%)	0.900	0.672-1.205	0.479
(185% - 200%]	94,479 (2.19%)	333,903 (2.38%)	0.530	0.346-0.811	0.00343*
(200% - 300%]	606,360 (14.07%)	2,147,619 (15.29%)	0.547	0.436-0.686	<0.001*
(300% - 400%]	472,823 (10.97%)	1,863,819 (13.27%)	0.518	0.400-0.670	<0.001*
>400%	935,345 (21.71%)	5,267,902 (37.52%)	0.346	0.281-0.427	<0.001*

Table 5. Factors independently associated with problems getting care by multivariable logistic regression

Variable	Adjusted Odds		
	Ratio	95% CI	p-value
Mental Health Disorder (Reference is No)			
Yes	2.111	1.714-2.599	<0.001*
Child Sex (Reference is Male)			
Female	0.922	0.793-1.071	0.287
Child Race (Reference is White)			
Black	1.599	1.291-1.979	<0.001*
Other	1.497	1.187-1.886	<0.001*
Child Ethnicity (Reference is Non-Hispanic)			
Hispanic	1.189	0.939-1.505	0.151
Child Insurance Status (Reference is No)			
Yes	0.372	0.257-0.538	<0.001*
Child Age	1.012	0.992-1.032	0.236
Mother Age	0.988	0.976-0.999	0.038*
Mother Education (Reference is Less than HS)			
High School Graduate	0.660	0.482-0.903	0.009*
More than High School	0.774	0.573-1.046	0.095*
Anyone in household employed? (Reference is No)			
Yes	0.883	0.707-1.103	0.274
Poverty level of this household based on DHHS poverty guidelines (Reference is <=100%)			
(100% - 133%]	1.350	1.010-1.805	0.042*
(133% - 150%]	0.941	0.585-1.513	0.801
(150% - 185%]	1.189	0.857-1.650	0.301
(185% - 200%]	0.757	0.479-1.197	0.234
(200% - 300%]	0.717	0.551-0.932	0.013*
(300% - 400%]	0.759	0.560-1.030	0.076
>400%	0.534	0.414-0.687	<0.001*

CHAPTER 5

DISCUSSION

Primary Findings

Children with MHD had significantly higher odds of missed/delayed care and parental reporting of problems getting specialty appointments. In children with a diagnosed mental disorder, mothers may perceive their child's mental health issues to be more important and other preventive services may be less of a priority. In addition to this, their increased usage of the health service line (mental healthcare specifically) may lead to the parent having less time to schedule a child for specialty care. Specialty care providers have quite limited schedule openings, and with the child's increased mental health needs, this may result in there being more difficulty in finding a time when all parties are available (Gupta, D. & Denton, B., 2008).

The added complexity of their health status leaves parents with less time to take their children to preventive and specialty visits, which may be perceived as less of an immediate importance than their receiving mental healthcare. Young children with MHD have been shown to be more difficult for parents to handle, increase parental stress, and increase perceived family dysfunction (Herring et al., 2006). As a result, these parents may not want to go through the hassle of taking their children to a preventive or specialty visit when they can instead take that time to address the child's more immediate needs and comforts.

The results of this study can be used to inform the development of programs which may reinforce the importance of children's preventative care, and strategies to remove any barriers to getting it. Preventative health and specialist pediatricians in

Philadelphia could work in conjunction with child psychologists and mental health providers to provide joint comprehensive care to children who have a higher chance of missing or delaying the care that they need. This could lessen any health disparity that may occur between children with and without MHD. These findings highlight a need to focus on finding ways to promote and provide all of the healthcare that a child needs. Children with MHD have many additional healthcare needs that other children may not, but they still need adequate preventative care. This may bring the specific needs of a population needing extra help to the attention of healthcare providers and outreach programs.

Secondary Findings

The Federal Poverty guidelines are calculated using yearly income and the number of individuals living in the household, and are based on calculations done by Families USA using data from the U.S. Department of Health and Human Services. These numbers are used to calculate eligibility for Medicaid and the Children's Health Insurance Program. Lower percentages indicate less income per person per household and higher percentages indicate more income per person per household ("Federal Poverty Level", 2017). The reference group for the analysis was children living in households less than or equal to 133% of the federal poverty level (FPL) (the group with the least income per person per household). Children living in households 200% FPL or lower did not have significantly different odds of missing/delayed care or problems getting specialty care than others. It is only the three groups that have the highest FPL that have significantly lower odds of missed/delayed care than those less than or equal to 133%.

This difference in rates of missed/delayed care is likely due to the lack of resources (both financial and social) that households have below the 200% federal poverty line (“Federal Poverty Guidelines”, 2017). Their time and resources, instead of being able to go to preventative care visits (which may be largely seen as non-vital to the survival of the child), must go to more immediate needs and stresses. Preventative care may take a back seat to ensuring that there is enough food for the child to eat, that the electricity stays on in the home, and that the child has a stable shelter. For these reasons, below this threshold the impact of their poverty does not significantly impact their odds of getting care. It is likely not until they have enough money to sufficiently cover all of their other needs that they can focus on things like preventative medicine. Above this level though, children living in households decrease their odds of missing care for each group of FPL that they go up in. Each of these increases in income per person per household affords families more resources which they can use to get their children preventative care, since other necessities can be more easily incorporated into the available budget.

Household employment was not found to be significantly associated with the odds of a child having missed/delayed preventive healthcare or problems getting specialist appointments in the past 12 months. The 2010 Affordable Care Act expanded public insurance to cover, without any cost sharing, an annual preventive healthcare appointment (Koh, H. & Sebelius, K., 2010). This means that families without a stable source of income do not need to worry about an expensive copay for their child’s appointment. Additionally, a review using articles published between 1985 and 2009 found that primary care providers were no more or less likely to give specialist referrals

to those who were unemployed compared to those who were employed (Harris, E. & Harris, M., 2009). It is not surprising then that we found no association between either outcome and the household employment status.

Maternal education, which is often used as a marker for socioeconomic status, played a significant role in the odds of a child having missed/delayed care (Winkleby, Jatulis, Frank & Fortmann, 1992). A study conducted using the National Health Interview Survey (NHIS) found that child healthcare utilization increased with increased maternal education (Hammen, Burge, & Adrian, 1991). Contrary to this and other research findings, our results suggest that children with more educated mothers have higher odds of having missed care in the past 12 months than children with less educated mothers. Expansions in Medicaid coverage and eligibility, however, have increased the healthcare utilization trends in adults (Sommers, Baicker, & Epstein, 2012). This trend may be contributing to an uptick in healthcare utilization in children.

Regarding reporting problems to getting specialist care, the opposite association existed for maternal education. More educated mothers had significantly less odds of reporting problems getting their child the specialist care that they require. Scheduling specialty appointments most often requires a referral from a primary care provider, and some specialties have a shortage of qualified physicians (Gupta, D. & Denton, B., 2008). This increased complexity, and lower availability of providers may make it more difficult to get appointments scheduled. Individuals with higher levels of education may live in areas with more access to specialty care, or have a greater understanding and tolerance of the process of navigating the complex specialty systems.

Mean maternal age did not significantly impact the odds of a child having missed/delayed care, however, it was significantly associated with problems getting care. Each unit increase in maternal age (years) was associated with a slightly lower odds of the child having missed/delayed preventive care. Missed/delayed care was not likely impacted by maternal age because of the relative simplicity of getting preventive care for a child, and due to Medicaid expansion helps ensure that most children are covered for their preventive visits. Additionally, a review of 58 large observational studies from 1994 to 2003 did not list maternal age as having a significant impact on child preventive care utilization (Chung, Lee, Morrison, & Schuster, 2006). Problems getting specialist care, however, was found to be significant. This is likely due to the increased complexity associated with getting a referral and appointment for specialist care, and older mothers being more likely to have more children and more experience navigating the healthcare system (Gupta, D. & Denton, B., 2008).

Mean child age was significantly associated with the odds of a child having missed/delayed care, however, it was not significantly associated with parental reporting of problems getting specialty appointments. As children increased in age, their odds of having missed/delayed care in the past 12 months increased by a small but statistically significant amount. Given that most of the child's required vaccinations are clustered near the earlier years, and become more sporadic as the child ages, this association is to be expected ("Child and Adolescent Schedule", 2017). Parents have more incentive to come to these visits because even if their child is otherwise healthy, they have an important reason to come. As the child ages, and less vaccinations are required, well visits may become less of an importance. Problems getting specialty visits, however, did

not have a significant association with child age. A 2012 telephone survey of 341 families also found no significant relationship between the age of the child, and parental reporting of problems getting care (Zuckerman, Perrin, Hobrecker, & Donelan, 2013).

Child insurance status was highly associated with both missed/delayed care and parental reporting of problems getting specialty appointments. Children who were uninsured had much higher odds of having missed/delayed preventive care and problems getting specialty care than their insured peers. Uninsured children have out-of-pocket costs associated with their care. Well care may not be seen as a priority when it has associated costs, and specialty care is very expensive when not partially covered by insurance (Gupta, D. & Denton, B., 2008; Perry, C., & Kenney, G., 2007).

The child's race was significantly associated with both missed/delayed care and parental reporting of problems getting specialty appointments. Specifically, compared to Whites, Black children had significantly higher odds of having missed/delayed care or problems getting specialty care. Children of race other than Black/White, however, had higher odds of problems getting specialty care, but not higher odds of missed/delayed care. This is in agreement with other research findings, where children of minority races, especially Black children, have been found to be less likely to visit a doctor's office for any reason (Hahn, B. A., 1995).

The ethnicity of the child was not associated with the odds of missed/delayed care or parental reporting of problems getting specialty care. Previous studies have found that while English speaking Hispanic populations do not have differing rates of care than non-Hispanics, Spanish speaking Hispanic populations have overall less utilization of the healthcare system (Fiscella, Franks, Doescher, & Saver, 2002). This may mean that the

relationship has little to do with ethnicity and is more related to being a non-English speaker.

Child sex was not associated with the odds of missed/delayed care or parental reporting of problems getting specialty care. A 2012 telephone survey of 341 families also found no significant relationship between the sex of the child and parental reporting of missing or having problems getting care (Zuckerman et al., 2013). This association may not be non-significant because most sex-specific reasons to utilize preventive care (pap smears for females, etc.) are not relevant to young children. Parents have equal incentive (immunizations, developmental screening) to get young children of both sexes to their preventive and specialty appointments.

Strengths and Limitations

Strengths of this survey include that the NSCH has a very large sample size and is weighted to be nationally representative. The survey implements RDD as a method of contacting potential enrollees, which has the benefit of including non-listed numbers that may be missed using other phone survey methodologies. Since the NSCH is cross-sectional in design, there are no long follow-up periods where enrollees can be lost. Upon completing the survey, all the data that is needed and available for a particular subject has already been collected. This allows for prevalence to be determined for the selected outcomes. As a result, the NSCH has a high capability to be representative of the population compared to other research designs. Because of this, the present study is not limited to be generalizable to only a specific subset of the population.

Limitations of the study include that the distribution of outcome variables needed to be reduced to binary due to low frequency of individuals perceiving a “big problem”

getting their child the care that they need (1.7%). As a result, the outcome was made to be “any problem” vs “no problem” which may result in a lack of nuance in the interpretation of results.

The NSCH has a relatively poor response and completion rate. 38.2% of eligible land lines responded, and of those only 54.1% completed the survey. 15.5% of eligible cell phone lines responded, and of those only 41.2% completed the survey. As a result, it is possible that certain populations are underrepresented in the sample. Weighting was used as a method for correcting any underrepresentation, but it cannot be known if there are certain populations who are under or not represented in the study.

Since the NSCH is a phone survey and asks patients to remember as far back as a year about their activities of daily living, there are a number of limitations and biases that may be present. Survey respondents may feel pressure to give favorable answers, or answers that present their child and how they care for them in a positive light. This may result in the under reporting of issues a child has. Due to the fact that parents/guardians are asked if a doctor has ever told them their child has any of these conditions, we are relying on them having gotten any care to begin with. Parents who struggle the most with their lives/children may not have gotten to the doctor to get their child diagnosed or may not remember the particularities if they have to be more concerned with more pressing issues (food, housing, etc.). This will result in the under reporting of issues a child/parent has. Finally, there is a potential for recall bias; if a child has had a visit, or the parent has had a “small issue” getting the visit, they may not remember the details of that visit if it was many months in the past.

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