

Do Children With Special Health Care Needs with Anxiety Have Unmet Health Care Needs? An Analysis of a National Survey

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ABSTRACT

Objective: To describe differences in health care needs between Children with Special Health Care Needs (CSHCN) with and without anxiety and examine the association between anxiety and unmet health care needs.

Methods: We analyzed data from the 2009/10 national survey of CSHCN. The independent variable was anxiety. The main outcomes were health care needs and unmet needs.

Covariates included demographics, other co-morbid conditions, and the presence and quality of a medical home. We used bivariate analyses and multivariable logistic regression to assess the relationships among anxiety, covariates, and the outcomes. We stratified our analysis by age (6-11 years, 12-17 years). Propensity score matched paired analysis was used as a sensitivity analysis.

Results: Our final sample included 14,713 6-11 year-olds and 15,842 12-17-year-olds. Anxiety was present in 16% of 6-11 year-olds and 23% of 12-17 year-olds. In bivariate analyses, CSHCN with anxiety had increased health care needs and unmet needs, compared to CSHCN without

anxiety. In multivariable analyses, only children 12-17 years old with anxiety had increased odds of having an unmet health care need compared to those children without anxiety (OR 1.44 [95% CI 1.17-1.78]). This was confirmed in the propensity score matching analysis (OR 1.12, [95% CI 1.02-1.22]). The specific unmet needs for older CSHCN with anxiety were mental health care (OR 1.54 [95% CI 1.09-2.17]) and well child checkups (OR 2.01 [95% CI 1.18-3.44]).

Conclusion: Better integration of the care for mental and physical health is needed to ensure CSHCN with anxiety have all of their health care needs met.

Significance Statement:

What is already known on this subject?

CSHCN are at increased risk for internalizing disorders and unmet health care needs, including mental health services. Anxiety is costly, prevalent, and under recognized in the pediatric population.

What this study adds?

CSHCN with anxiety ages 12-17 had increased odds of having an unmet health care need compared to children without anxiety even when adjusting for all confounders. The specific unmet needs for older CSHCN with anxiety were mental health care and well child checkups.

Key words: Children with Special Health Care Needs, anxiety, unmet health care needs, mental health

INTRODUCTION

Children with special health care needs (CSHCN) are a large population of children (Bethell, Read, Blumberg, & Newacheck, 2008) in the U.S. (12 million) who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services” requiring a higher level of care than children would generally require. (Bethell et al., 2008; McPherson et al., 1998) Despite high levels of health care utilization, CSHCN have high rates of unmet health care needs which are differences between services believed to be necessary to appropriately care for a health care problem and services actually received. (Bitsko et al., 2009; Chiri & Warfield, 2012) (Pappa, Kontodimopoulos, Papadopoulos, Tountas, & Niakas, 2013) The demographic factors most strongly related to unmet health care needs among CSHCN are poverty, lack of insurance, race, and membership in an ethnic minority group. (Houtrow, Okumura, Hilton, & Rehm, 2011) Specific diseases have also been found to increase a CSHCN’s odds of having unmet needs: autism; emotional, behavioral, developmental problems; and combined mental and neurologic disorders.(Bitsko et al., 2009; Chiri & Warfield, 2012)

CSHCN have a higher prevalence (32%) of internalizing mental health (MH) problems than children in the general population (up to 20%) which include both depression and anxiety. (Ghandour, Kogan, Blumberg, & Perry, 2010) Anxiety is the most common lifetime MH condition (14-25%) with rates up to 20% reported in children in the general population; yet it can be challenging to diagnose since clinicians need to distinguish between true anxiety disorders and developmentally and situationally appropriate anxiety.(Ramsawh, Chavira, & Stein, 2010) Anxiety often presents in school-aged children with physical complaints which may impede recognition and delay diagnosis.(Dillon-Naftolin, 2016) Therefore, anxiety in children is often

under-recognized and, if recognized, inadequately treated. This is despite evidence that anxiety is treatable, and, if untreated, can cause morbidity in adulthood.(Merikangas et al., 2011; Ramsawh et al., 2010)

In addition, co-morbid anxiety is prevalent in children with chronic physical health conditions which leads to worse physical disease control and quality of life.(Perrin, Gnanasekaran, & Delahaye, 2012; Roy-Byrne et al., 2008) For example, in one study, 25% of children with inflammatory bowel disease (IBD) with co-morbid anxiety had more severe flares, more relapses, and higher health care utilization.(Reigada, Moore, Martin, & Kappelman, 2018) Children with asthma and co-morbid anxiety have worse disease control, miss more days of school, and have more hospitalizations.(Bruzzese et al., 2016) In addition, children with any MH problem as either a primary or co-morbid condition have high rates of unmet health care needs, specifically MH services.(Ganz & Tendulkar, 2006; Merikangas et al., 2011) However, no study has focused on unmet health care needs in children with anxiety.

Despite a national push to better integrate MH care into the pediatric medical home,(American Academy of Pediatrics, 2009) there has been less national attention in addressing childhood anxiety specifically. Clinical guidelines for the primary care management of ADHD, maladaptive aggression, and depression have been created for general pediatricians, (Knapp et al., 2012; Wolraich et al., 2011; Zuckerbrot et al., 2007) but do not exist for anxiety. Also, national recommendations to screen for adolescent depression exist, but none currently do for anxiety.(US Preventive Services Task Force, 2016) Lastly, health care experiences of children with anxiety have not been well described and there has not been an opportunity to evaluate these experiences in a large sample until recently.

For the first time, the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) asked parents if their children had anxiety problems as a separate question from other internalizing disorders, affording an opportunity to study this problem in a large national sample of CSHCN. In this national sample 4.7% of CSHCN had anxiety as their only health problem, and 12.3% had anxiety as a co-morbid condition in addition to another physical or MH condition. (U.S., Department of Health and Human Services, & Administration, 2009-2010). A better understanding of the needs and unmet needs of CSHCN with anxiety could help facilitate several potential interventions, such as national efforts to standardize care for identifying and attending to the needs of CSHCN with anxiety.

Anderson's Behavioral Model of Health Services Use is a conceptual framework to evaluate health care utilization and has informed analyses in other studies of CSHCN and health care needs.(Babitsch, Gohl, & von Lengerke, 2012; Chiri & Warfield, 2012) In this framework, predisposing characteristics (demographics, education, ethnicity, health beliefs), enabling factors (income, insurance, medical home, availability of resources), and need factors (perceived and evaluated need/presence of a health care problem) are the components believed to drive health care utilization. As stated above, variables in each of these categories have been associated with unmet needs in CSHCN.

This study focused on whether anxiety as the health care problem drives need and receipt of health care services. After accounting for predisposing, enabling, and need factors as per Anderson's model, our primary research question was to look for an association between anxiety and unmet health care needs. The objectives of this study were: 1) To describe differences in health care needs between CSHCN with and without anxiety and 2) to investigate the association

between anxiety and unmet health care needs controlling for demographics, other co-morbid conditions, and the presence and quality of a medical home.

METHODS

Study Design

Using a cross sectional study design, we performed bivariate logistic regression, and propensity matched analyses on a nationally representative sample of CSHCN to assess the independent relationship between anxiety and unmet health care needs. The Institutional Review Board at Weill Cornell Medicine reviewed and approved this study.

Data Source

The 2009/10 National Study of Children with Special Healthcare Needs is a national, random digit dialing (RDD), cross-sectional survey that sampled households of all 50 states and the District of Columbia for children under 18 years of age.(U.S. et al., 2009-2010) A RDD of landline telephone numbers was performed with an independent RDD sample of cell-phones for households that reported a cell-phone as their only or main source of communication. The response rate was 25.5%. If more than one CSHCN was identified in the household, an interview was performed for only one randomly selected child. 40,242 interviews were completed of families of CSHCNs, 39% of the 102,802 children identified with special health care needs, including at least 750 in each state. A child had special health care needs if the survey respondent answered yes to one of the five items on the Children with Special Health Care Needs Screener: (1) the need or use of prescription medications, (2) increased use of medical care, MH, or educational services compared with other children, (3) limitations in activities, (4) need for specialized therapies (physical, speech, occupational) and (5) presence of emotional,

developmental, or behavioral problems for which the child needs treatment or counseling and that has lasted or will last 12 months or more.

Inclusion / Exclusion Criteria

We included respondents for all children 6 – 17 years of age. We excluded children 0 – 5 because (1) parents of children ages 0-2 were not asked about anxiety, and (2) the publicly available data did not distinguish between children 0-2 and 3-5. We did not include 2,902 respondents who had missing values for any of the variables of interest.

Predictor Variable

Anxiety was assessed on the survey by asking, “For the following list of conditions, has a doctor or other health care provider ever told you that [CHILD’S NAME] had the condition, even if [he/she] does not have the condition now? If yes, does [CHILD’S NAME] currently have the condition.” The predictor variable included parents who reported ever being told by a doctor that the child had anxiety.

Outcome Variable

The NS-CSHCN survey asked about 14 health care needs. Respondents answered yes or no to whether they needed the following services: a well child checkup; preventive dental care; other dental care; specialty care; prescription medications; physical, occupational, or speech therapy; MH care or counseling; substance abuse treatment or counseling for children ages 8-17; home health care; eyeglasses or vision care; hearing aids or hearing care; mobility aids or devices for children 3-17 years; communication aids or devices for children 3-17 years; durable medical equipment. For each needed health service, parents were asked if that health service had been received. A child had an *unmet health care need* if the parent indicated the child needed a healthcare service but did not receive it.

Covariates

Predisposing Factors: *Race / Ethnicity* were divided into four categories: Hispanic, White non-Hispanic, Black non-Hispanic, and other non-Hispanic. We divided *age* into two categories: 6-11 and 12-17, since transitions to care questions only applied to children 12-17 years. *Gender* was binary (male/female). We separated *family structure* into four categories: 2 parent household (biologic or adopted), 2 parent step family, mother only, or other. We categorized *primary language* as English or not English and *parental education* into three categories: less than high school, high school graduate, or more than high school.

Enabling Factors: *Insurance status* was collapsed into five categories: private only, public only, both public and private, uninsured, or “other comprehensive insurance.” We divided *poverty* into four categories based on income according to the percentage of Federal Poverty Level (FPL): Income 0-99% of the FPL, 100 – 200% of FPL, 200-400% of FPL, and greater than 400% of FPL. Income was determined based on responses about salary from interviews. We included six *quality of care* indicators as independent variables to account for experiences with health care, given that quality of a medical home is associated with attainment of health care needs and acts as variables to describe the context in which care is received. (Spears, 2010) These indicators were: shared decision making with physician, presence of medical home, adequate insurance, sufficient preventive care, easy access to community services, and adequate support of transition to adult care. The final indicator (transition to adult care) was only measured for adolescents (age 12-17).

Perceived/Evaluated Need: We determined an estimate of the overall health care needs of the child by counting the *number of needs* – i.e. the number of “yes” answers to the 14 specific health care needs included in the survey. We also included binary indicators for each of 20

specific comorbid disorders asked in the survey. Physical health conditions included: asthma; diabetes; heart problems including congenital heart disease; blood problems such as sickle cell disease; cystic fibrosis; arthritis or other joint problems; or allergies. Neurologic conditions included: epilepsy or seizure disorder; migraine or frequent headaches; head injury, concussion, or traumatic brain injury; cerebral palsy; muscular dystrophy; or Down Syndrome. We included vision and hearing difficulties based on parental response to these questions: “Would you say (he/she) experiences a lot, a little, or no difficulty with any of the following: Seeing even when wearing glasses or contact lenses? Hearing even when using a hearing aid or other device?” MH conditions included: attention deficit/hyperactivity disorder (ADHD); depression; behavioral or conduct problems; autism spectrum disorder; developmental delay; intellectual disability; or mental retardation.

Analysis

All analyses were carried out for age 6-11 years and age 12-17 years separately. We calculated summary statistics using frequencies and proportions for categorical variables and medians and interquartile ranges for continuous variables. The nationally representative numbers were estimated using sampling weights provided in the CSHCN database. Demographics, quality of care, and comorbidities were compared between CSHCN with anxiety and CSHCN without using chi-square tests for categorical variables and Wilcoxon-Mann-Whitney tests for continuous variables using Bonferroni corrections to account for the multiple comparisons. Association between any unmet health care need and anxiety was assessed using multivariable logistic regression models, weighted with the CSHCN database sample weights, and adjusted for covariates. Factors included in the multivariable regression models were race, gender, insurance,

household members, language, parental education, poverty level, quality of care indicators, and medical, neurologic and mental health comorbidities.

To further explore the association between each of the 14 unmet health needs and anxiety, a series of weighted multivariable logistic regression models were fit to assess the independent effect of anxiety on each unmet need. Models were adjusted for all covariates mentioned above. Results from the multivariable logistic regression models were reported as odds ratios (ORs) with 95% confidence intervals (CIs). Variances were estimated by incorporating sampling weights to account for unequal selection probabilities.

To evaluate the robustness of our findings, a sensitivity analysis was conducted using propensity score matching for our primary outcome any unmet health need. Propensity score matching creates case and control groups with comparable conditional probabilities of anxiety. This matching technique can help estimate the effect of anxiety alone by accounting for all observed covariates that may also impact unmet health care needs. This technique is commonly used to mitigate bias that may exist due to confounding outcomes (demographics, socioeconomic status, number of needs, quality indicators, and co-morbid mental and physical disorder). (Rubin & Thomas, 1996)

The propensity score analysis was performed as follows. For each age strata, we developed a multivariable logistic regression model to estimate a child's propensity for anxiety that included demographics, quality of care, and comorbidities. CSHCN were then matched using a 1 to 2 greedy matching algorithm with replacement and with a caliper distance of 0.2 of the standard deviation of the logit propensity score. The standardized mean difference assessed the balance of covariates between anxiety groups before and after propensity score matching. Covariates with standardized mean differences of less than 10% were considered balanced

between groups. Exact matching was used for asthma and depression since the propensity score matching did not achieve sufficient balance for these characteristics. Conditional logistic regression was used to assess the association between anxiety and any unmet health need. This sensitivity analysis was carried out without sampling weights to simplify the interpretation. All statistical analyses were performed with SAS version 9.4 (SAS Institute, Cary, NC). Two-sided p values < 0.05 were considered significant.

RESULTS

Sample

30,555 respondents were included in our analyses. Of the 14,713 respondents in the 6-11-year-old group, 16% had anxiety and of the 15,842 respondents in the 12-17-year-old group, 23% had anxiety. The 6,785 respondents in the 0-5-year-old group were excluded as were 2,902 respondents for missing data (Figure 1).

Table 1 illustrates characteristics of the sample for both age groups and bivariate analyses between CSHCN who had anxiety compared to CSHCN who did not. In this cohort, CSHCN in both age groups with anxiety were more likely to be white, male, publicly insured, and living below the FPL. They were less likely to live in a 2-biologic parent household or report they achieved quality care in any of the 6 indicators. CSHCN 6-11 years with anxiety were more likely to be English speaking, and CSHCN 12-17 years were more likely to have a parent with less than a high school education. CSHCN with anxiety also were more likely to have migraines and each of the other MH conditions.

For the sensitivity analysis (Appendix), our final sample was as follows. For 6 – 11 year old, we included 2,196 CSHCN with anxiety, matched with 4,329 CSHCN in the same age group without anxiety. For 12-17 year olds, we included 3,003 CSHCN with anxiety matched with

6,006 CSHCN without anxiety. Cohort characteristics were well balanced between the case and control groups. Standardized differences in means (standardized bias) were below 10 percent (0.1) for all variables.

Needs of CSHCN With and Without Anxiety

CSHCN with anxiety had more health care needs than CSHCN without anxiety (Table 1). CSHCN ages 6-11 with anxiety had 3.26 [95% CI 2.24-4.64] needs vs. 1.97 [95% CI 1.06-3.08] for CSHCN without anxiety, $p < 0.001$. CSHCN ages 12-17 also had more needs: 3.47 [95% CI 2.40-4.62] vs. 2.28 [95% CI 1.32-3.36], $p < 0.001$. We found several differences in the types of health care needs among CSHCN 6-11 and 7-12 years old with and without anxiety (Figure 2). CSHCN 6-11 years with anxiety had a greater need for 9 of 14 health care needs. CSHCN 12-17 years with anxiety had a greater need for 10 of the 14 health care needs. The largest difference in needs between CSHCN with anxiety compared to CSHCN without was the percentage that needed MH care or counseling: 75% of CSHCN with anxiety needed MH care or counseling vs. 20% without anxiety ($p < 0.001$).

Unmet Needs of CSHCN With and Without Anxiety

In the bivariate analysis, 44% [95% CI 40.1-47.2] of CSHN ages 6-11 years with anxiety vs. 25% [95% CI 23.2, 26.3] without anxiety had any unmet need, $p < 0.001$ (Table 1). However, this difference was not significant after accounting for confounding variables in the weighted multivariable logistic regression (Table 2). Number of needs was the confounder in the regression that weakened the association between anxiety and unmet needs for this younger age group. While having *any* unmet need was not significantly associated with anxiety in this age group, CSHCN did have an unmet need for MH care or counseling (OR 1.7 [1.14-2.46], $p < 0.01$) and prescription medications (OR 2.2 [1.28-3.70], $p < 0.01$). Of note, CSHCN with anxiety ages

6-11 had decreased odds of having an unmet need for home health services (OR 0.15 [95% CI 0.04-0.56], $p < 0.01$).

For children aged 12 – 17, 49% [95% CI 45.8-52.0] of CSHCN with anxiety vs. 24% [95% CI 22.3-25.3] without anxiety had any unmet need in bivariate analyses, $p < 0.001$ (Table 1). This association remained in this age group when accounting for confounding variables in the regression analysis (OR 1.44 [95% CI 1.17-1.78], $p < 0.001$) (Table 2). This finding was confirmed with the propensity scored matched cohort (OR 1.12 [9% CI 1.02-1.220] $p = 0.02$). The most common unmet needs in CSHCN with anxiety in this age group were for MH care or counseling (OR 1.54 [95% CI 1.09-2.17], $p < 0.05$) and a well child checkup (OR 2.01 [95% 1.18-3.44], $p < 0.05$).

Discussion

Summary/Interpretation

After accounting for predisposing, enabling, and need factors associated with health care utilization, we found that CSHCN ages 12-17 years with anxiety had 1.4 increased odds of having *any* unmet health care need, compared to CSHCN without anxiety. These findings were also supported by a sensitivity analysis using propensity score matching. The propensity analysis was done to look at anxiety separately from the needs of other conditions and the impact of enabling and predisposing factors on disease prevalence. For instance, in our data, CSHCN living in poverty and on public insurance were more likely to have anxiety, which is consistent with evidence that physical and MH problems are more common in children with these characteristics. (Dreyer, 2013) Our results demonstrate the association of anxiety and unmet needs regardless of other factors. The effect size decreased with propensity score matching which is not surprising given the large percentage of CSHCN with anxiety having co-morbid

MH conditions present in the analysis. In contrast to CSHCN ages 12-17, the association between anxiety and any unmet health care need was not found after controlling for confounders in CSHCN ages 6-11 years. Further study is needed to elucidate the differences of needs and unmet needs in CSHCN with anxiety between age groups.

Anxiety is known to be associated with unmet health care needs in adults,(Baldwin, Pallanti, & Zwanzger, 2013) but our findings demonstrate this association in CSHCN for the first time. The causal direction of the association between unmet needs and anxiety is unclear. Our results demonstrate a large difference in the number of needs and unmet needs for MH care in both age groups for CSHCN with and without anxiety, suggesting that anxiety may be the health care problem driving a need for services that are not met. Unmet need for MH services is not novel in CSHCN. (Ganz & Tendulkar, 2006) Epidemiologic studies have shown that youth with anxiety are less likely to receive appropriate services than children with other MH problems, like ADHD, supporting the idea that care for that anxiety is the main unmet need.(Merikangas et al., 2011) Anxiety screening and treatment has been successfully integrated into primary care in adult medicine and in some subspecialty practices; (Davidson, Feltner, & Dugar, 2010; Reigada et al., 2017) yet practicing pediatricians are less confident in treating anxiety compared to other disorders.(Stein et al., 2008) Regardless of the direction of the association between anxiety and unmet health care needs, clinicians should be assessing for unmet needs in CSHCN with anxiety, and CSHCN with unmet needs should be evaluated for anxiety.

CSHCN with DSM conditions have been shown to have unmet needs for physical health services such as prescription medications in prior studies.(Bitsko et al., 2009) These findings are specific to anxiety as the DSM condition driving unmet needs for prescription medications. Perhaps parents perceive a need for medications to help with their child's physical symptoms

when in fact the symptoms are manifestations of anxiety not requiring medications. For instance, CSHCN with anxiety in both age groups had a significant increase in co-morbid headaches which is a common presentation of anxiety in children. (Dillon-Naftolin, 2016)

CSHCN ages 12-17 with anxiety have more unmet needs for well child checkups which is not surprising, since adolescents often have poor access to a medical home.(Adams, Newacheck, Park, Brindis, & Irwin, 2013; Nordin, Solberg, & Parker, 2010) In addition, a recent study found that parents who report seeing a specialist were less likely to bring their adolescent child to annual preventive care visits and often prefer contacting their subspecialists instead of their pediatricians with questions.(Aalsma, Gilbert, Xiao, & Rickert, 2016) However, to what extent subspecialists address psychosocial and MH issues is unknown and these issues may be under emphasized when they are the primary point of contact.

Limitations

Several limitations merit discussion. This cross-sectional study design allowed us to examine associations, but not to infer causation. In addition, our main predictor variable, the presence of anxiety, was collected by parental report which could lead to a recall bias. Parents often under-report their child's anxiety symptoms especially when compared to the child's report, which could have also lead to a lower prevalence of anxiety in the sample.(Bajeux et al., 2018; Rimmer et al., 2014) Conversely, parents may have responded "yes" for children with non-pathological, developmentally appropriate anxiety. Sampling biases must also be considered since the national survey for CSHCN under-samples some populations, such as parents who do not speak English and parents who have less than a high school education. Lastly, given the way the survey was designed and questions were asked, it is unknown whether

caregivers' responses to services needed were a "perceived" or "evaluated" need, as specified in Anderson's conceptual framework.

Implications

Despite the limitations these data support the need to provide a holistic approach to all CSHCN. Since the evidence on the interplay between disease and environment and physical and mental health is increasing,(Garner, Shonkoff, Health, Committee on Early Childhood, & Pediatrics, 2012) all aspects of a child's health needs to be addressed at each visit through multidisciplinary teams in both the primary medical home, and in the subspecialists' office. CSHCN with a medical home, an enabling factor, have fewer unmet needs because it increases access to services and improves coordination of care, both of which are achieved in integrated models of care. (Boudreau et al., 2014; Homer et al., 2008) Practices have begun to develop integrated models of care with an onsite MH professional into pediatricians' (both general and subspecialists) practices which can improve access to care and patient outcomes.(Richardson, McCarty, Radovic, & Suleiman, 2017; Samsel, Ribeiro, Ibeziako, & DeMaso, 2017) However, funding for collaborative care models is inconsistent since no financial structures regularly support this type of care. Advocacy efforts are needed in order to develop and study integrated models of care in CSHCN with anxiety in order to change payment structures. National organizations for subspecialties, such as endocrinology and oncology, are developing guidelines to integrate psychosocial aspects of care into their practice.(Delamater et al., 2014; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015) These and other efforts to disseminate, implement, and evaluate guidelines are promising, and need study.

CONCLUSIONS

Our results suggest that among CSHCN ages 12- 17, anxiety has an independent association with unmet health care needs. Childhood anxiety has been largely unaddressed in physical health settings and barriers to care exist, especially access to MH services. Anxiety must urgently be a priority on the national agenda, especially in this vulnerable population. Integrating anxiety care for CSHCN in the medical home and/or in subspecialty practices through collaborative care models can improve access to care which would improve disease outcomes, quality of life, and costs on society.(Richardson et al., 2017) National clinical guidelines on addressing anxiety, advocacy for insurance coverage for all aspects of care for CSHCN and children with anxiety, improved education for pediatricians, and further research on collaborative care models are needed to improve the care of CSHCN and anxiety.

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