

Affect Family Time Burden?

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Abstract

Problem: Knowing which families are aware of the recommended types of services for mental health care, and which have unmet need can help identify groups to target for additional services. Assessing the impact of unmet need on family time burden is important for capturing oftenoverlooked aspects of inadequate health care service delivery.

Methods: We used cross-sectional data from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to estimate multinomial regressions to identify factors that predict a report of need and unmet need for mental health care (MHC) and prescription medication (Rx meds) among children with anxiety. We estimated multivariate OLS regressions to assess whether unmet need was associated with increased family time burden providing and arranging health care for the child with anxiety.

Results: Several health status, system, and demographic factors predict increased risk of a child's family not reporting a need for recommended treatment for anxiety. Children with anxiety who did not have a medical home were more likely to have unmet needs for either service. Those with unmet need for mental health care or Rx medication had families that spent about twice as much time providing or arranging or coordinating health care as those with their needs for both services fully met.

Conclusions: Unmet need for mental health care or counseling and prescription medication increases time burden. Unmet need for both services was associated with the greatest time burden.

Emily's Story

Emily is a 13-year old girl with severe anxiety, which is the most common mental health problem among children and adolescents in the United States¹. Common anxiety symptoms include:

- Feelings of apprehension or dread, irritability
- Insomnia, tremors

To manage Emily's condition: the recommended treatment combines²

- Seeing a psychologist, once a week for Cognitive Behavioral Therapy
- Taking medication such as Zoloft, Prozac, or Xanax

Demands on family time: In order for her to get the care she needs, Emily's family must:

Arrange and coordinate her care

- Schedule appointments for her weekly therapy and monthly prescription renewal with her psychiatrist.
- Coordinate care with and among her health care providers

Provide health care for her at home:

Supervise her taking her medicines

When Emily doesn't get the care she needs

- She doesn't get her medications, her symptoms become more severe.
- Her mother spends extra time coaching her on relaxation techniques to manag her symptoms.

Prior Literature on Consequences of Unmet Need

Unmet need for health care services I Only 31% of children with

anxiety receive adequate treatment³ Unmet need is associated with4

- Worse mental health
- Lower quality of life

Family burden is related to⁵

- Long gaps in mental health treatment
- Poor service utilization
- Treatment dropout

Research Questions

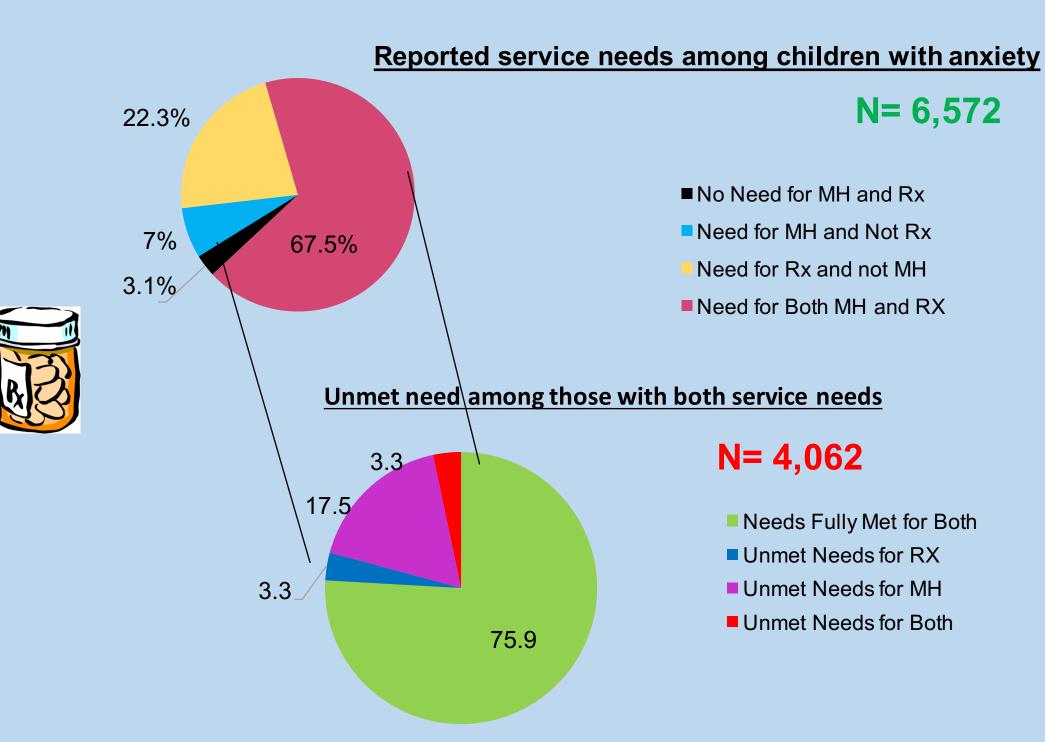
- What factors predict a parent's report of need for mental health care and prescription medication among children with anxiety?
- What factors predict a parent's report of unmet need for mental health care and prescription medication among children with anxiety?
- Among children with anxiety, what is the prevalence of unmet need for
- Mental Health care or Counseling
- Prescription Medication?
- Does unmet need for these health care services increase family time burden?
- Is the effect on time burden different based on unmet need for mental health care or counseling or unmet need for prescription medication?

Methods

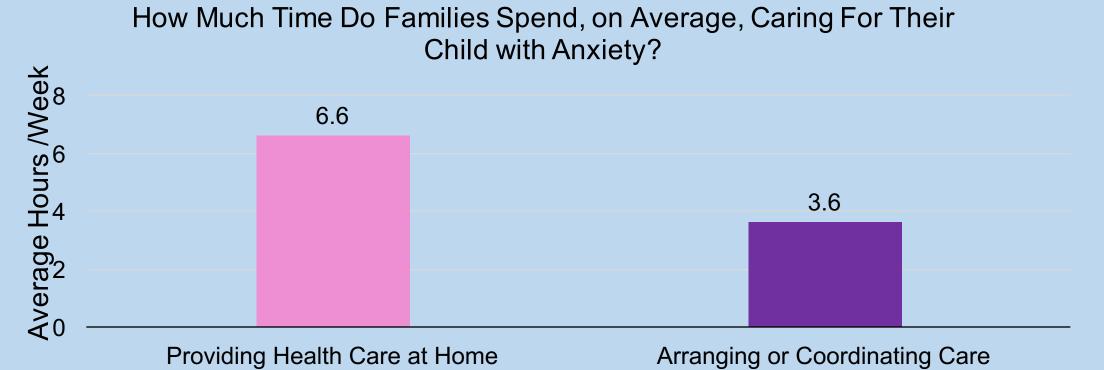
- Data are from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN)
- Study design: Cross-Sectional Telephone Interview Random Digit Dialing
- Respondents were parents or most knowledgeable adult in household about child's health/ health care
- A "Child with Special Health Care Needs has 1 or more of:
- 1) Use or need of prescription medication. 2) Above average use or need of medical, mental health or educational services.
- 3) Functional limitations compared with others of same age.
- 4) Use or need of specialized therapies (OT, PT, speech, etc.).
- 5) Treatment or counseling for emotional or developmental problems

Analytic Sample

- Overall survey sample = 40,242 respondents
- Inclusion Criteria for our analysis
- Currently have anxiety; age 5 years or older N= 6,572
- Have a need for both services N=4,383
- Complete information on all variables N= 4,062



Dependent Variables = family time burden



Type of Family Time Burden

Control Variables (reference category in red)

Health Status Factors:

- Severity of Anxiety: Mild: (44%), Moderate (41%), Severe (15%)
- Stability of Child's healthcare needs: Change all the time (15%), Change once in a while (40%), Usually stable or none of the above (45%)
- Daily Activity Limitations: Never affected (13%), Moderately Affected (35%), Consistently affected (52%)

Comorbidity:

Count: Anxiety only (5%), 1 Comorbidity (14%), 2+ comorbidities (82%) **Type:** Comorbid mental health condition (86%), Comorbid physical condition (71%); Comorbid Developmental condition(40%)

Enabling Factors:

- **Medical Home**: No medical home (70%)
- Insurance Type: Private (44%), Public (39%), Public & Private (11%), Other (3 %), Uninsured (3%)
- **Insurance continuity:** Not insured at some point during year (10%)
- Family Income Level (% of FPL): <133% (33%), 133-199 (16%), 200-299% (15%), 300-399%(12%), >400% (24%)

Predisposing Factors:

- Race: Non-Hispanic White (67%), Hispanic (16%), Black(9%), Non-Hispanic Other (8%) **Sex**: Male (61%)
- **Age** (Years): 5-11(42%) 12-17 (58%)

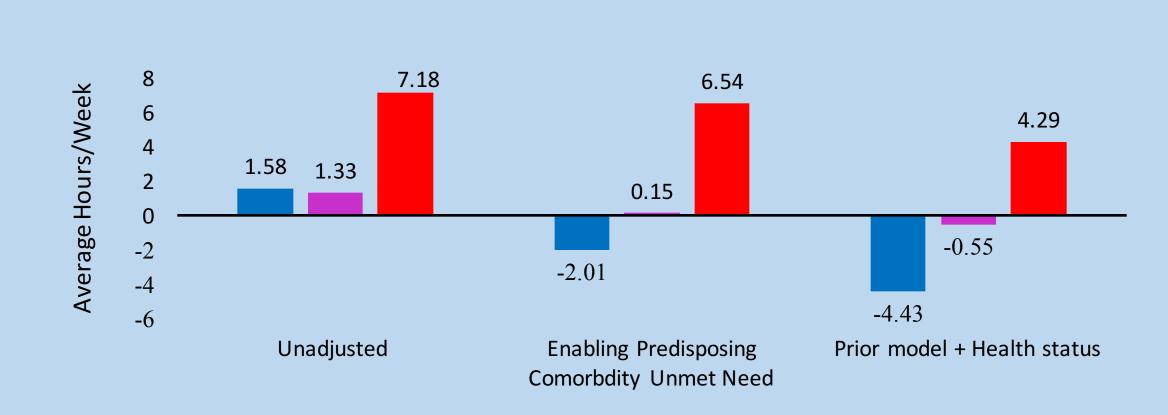
Which families of children with anxiety are more likely to not report a need for the recommend treatments for anxiety?

- When a child's condition consistently or moderately affects their activity
- Being uninsured compared to private & other comprehensive insurance
- Having a family income <200% of the federal poverty level compared those with an income greater than 400% of the federal poverty level
- Having less than a high school education
- Being Non-Hispanic Black compared to Non-Hispanic White.

What predicts increased risk of unmet need for mental health care and/ or prescription medication?

- Having moderate or severe anxiety
- Having a comorbid mental or physical health condition
- Being uninsured compared to private & other comprehensive insurance
- Those who have had gaps in insurance coverage
- Not having a medical home

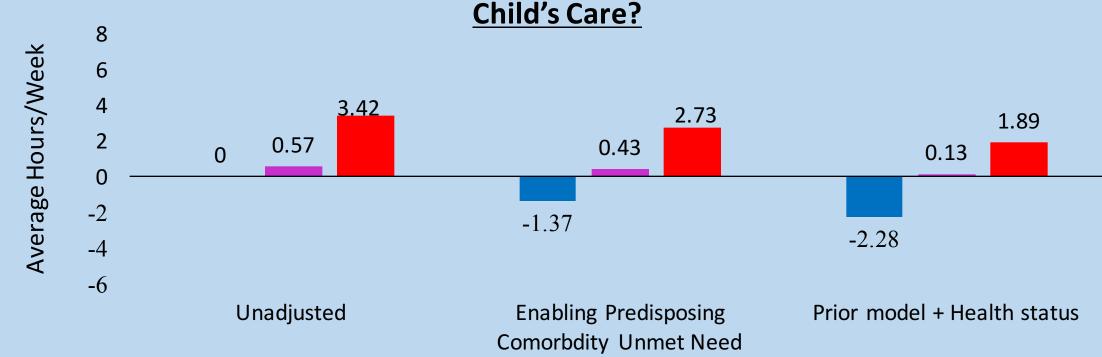
Does Controlling for Health Status, Enabling and Predisposing Factors Reduce Excess Time Spent Providing Health Care at Home?



Unmet need for prescription medication only ■ Unmet need for mental health care or counseling only

■ Unmet need for both services

Does Controlling for Health Status, Enabling and Predisposing Factors Reduce Excess Time Spent Arranging or Coordinating a **Child's Care?**



What Other Characteristics Increase Time Burden?

compared to reference category	Providing Health Care at Home	Arranging & Coordinating Care
Severe anxiety (Ref: Mild)	1 Hours/Week	41 Minutes/Week
2 or more comorbid disorders (Ref: 1 comorbid)	2 Hours/ Week	1 Hour/ Week
Daily activity consistently affected (Ref: Never)	5 Hours/Week	2 Hours/ Week
Public Insurance (Ref: Private)	3 Hours/Week	1 Hour/Week
Income <133% of FPL (Ref: >400% of FPL)	2 Hours/Week	1 Hour/Week
Hispanic (Ref: Non-Hispanic White)	2 Hours/Week	1 Hour/Week
5-11 Years old (Ref: 12-17)	2 Hours/Week	43 Minutes/Week

FPL: Federal Poverty Level Medical home: Child must have

- 1)Usual source of care 2) Personal doctor or nurse
- 3) No problems getting referrals 4) Coordinated Care
- 5) Family-centered care

Main Findings

- Poor health status, low SES and lack of health insurance predict lack of parental awareness of recommended health care services for children with anxiety.
- Severe anxiety, presence of comorbid health conditions, lack of health insurance or medical home are associated with increased risk for unmet need for recommended services.
- Unmet need for **both medication and therapy** services was associated with the largest increase in family time burden (34 extra minutes / day providing care, 17 extra minutes/ business day arranging or coordinating care).
- Unmet need for mental health care was a stronger predictor of increased family time burden than unmet need for prescription medication.
- Unmet need increased time spent providing care more than time spent arranging care



Study strengths

- Large nationally representative sample
- Large number of cases of children with anxiety
- Ability to control for many potential confounders such as measures of medical need, socioeconomic factors
- Measures two aspects of unmet need that relate to specific recommended treatments for anxiety
- Mental health care or counseling
- Prescription medication
- Differentiate between different types and combinations of unmet

Study limitations

- Parent's report of anxiety/ and severity of condition
- May not be consistent with clinical diagnosis Anxiety may result from other comorbid disorders
- Parent's report of need/unmet need
- There is no consistent definition of need/ unmet need
- o 19% of children with severe anxiety had been reported as not having a need for both services
- Cross-sectional- can't determine causality

Implications

- Quality care guidelines recommend prescription medication only when coupled with counseling or therapy.
- If parents are unaware of recommended services for anxiety, they are unlikely to seek them for their child.

Health care practitioners can use these findings to recognize potential

- risk factors that would prevent a family from seeking and/or receiving appropriate care for their child's condition. Health policymakers can use these findings to recognize the
- importance of a child's access to care and its impact on their families
- By increasing access to medical homes \rightarrow decrease unmet needs \rightarrow decrease family time burden.

Directions For Future Research

- Assess whether unmet need mediates the effects of health status, health system, or demographic factors on family time burden.
- Include unmet need for other health services relevant to anxiety
- Primary care
- Specialty care

Citations

Mechanisms, Assessment, and Treatment. Journal Of Child And Adolescent Psychiatric Nursing, 28(3), 131-140. doi:10.1111/jcap.12116 Anxiety and Depression Association of America, 2016

Norman, K., Silverman, W., & Lebowitz, E. (2015). Family Accommodation of Child and Adolescent Anxiety:

- Chavira, D. A., Stein, M. B., Bailey, K., & Stein, M. T. (2004). Child anxiety in primary care: Prevalent but untreated. Depression & Anxiety (1091-4269), 20(4), 155-164. doi:10.1002/da.20039 Slade, M., Leese, M., Cahill, S., Thornicroft, G., & Kuipers, E. (2005). Patient-rated mental health needs and
- quality of life improvement. British Journal Of Psychiatry, 187256. Inkelas, M., Raghavan, R., Larson, K., Kuo, A., & Ortega, A. (n.d). Unmet mental health need and access to services for children with special health care needs and their families. Ambulatory Pediatrics, 7(6), 431-438.

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