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Parent-Child Agreement in the Reporting of Headaches in a National Sample of Adolescents

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Abstract

The aim of this article is to assess the concordance between parent and adolescent headache ratings in a representative sample of 6483 US adolescents (aged 13–18 years). Headaches were assessed using modified criteria from the International Headache Society's International Classification of Headache Disorders, Second Edition. Caregiver report was based on a self-administered questionnaire. Overall concordance between caregivers and adolescents on the presence or absence of headaches was quite low ($\kappa = 0.39$). Female caregivers were twice as likely as male caregivers to report headaches in their offspring. Positive endorsement of headaches in offspring by caregivers was associated with adolescent-reported chronic headaches, longer headache duration, and photophobia or phonophobia. These findings suggest that relying solely on parent report may result in an underestimate of the true prevalence of headaches in the general population. In addition, collecting information from both parents and adolescents could be critical to effective treatment and prevention of the severe consequences of migraine.

Keywords

headache; migraine; concordance; National Comorbidity Survey-Adolescent Supplement

Headaches are one of the most common health problems in adolescents, with a range of 5% to 25% of children and adolescents reporting severe or frequent headaches.^{1,2} The impact of headaches on young people is substantial and includes lower ratings of quality of life, poorer physical and mental health, and more days of missed school. Children and adolescents

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suffering from headaches have poorer quality of life than both the established healthy norms³ and children with asthma, diabetes, cardiac diseases, and cancer.^{4,5} In addition, headaches have been shown to be comorbid with a range of physical and mental health problems, including asthma,⁶⁻⁸ allergies,⁶⁻⁸ sleep disorders,^{9,10} suicidal ideation,¹¹ emotional and behavioral problems,¹² and depression and anxiety.¹³ The high level of physical comorbidity in youth with headaches is associated with greater levels of impairment than children without headaches.⁶ In the National Health Interview Survey, a population-based sample of 47 711 US households, 10% of children with migraine headaches missed at least 1 day of school, and almost 1% missed 4 days during a 2-week period.¹⁴ Given the significant impact of headaches on the health and well-being of young people, it is important for medical providers and researchers to understand methods for accurate diagnosis of children and adolescents and to enhance recognition of headache syndromes by youth and their parents to facilitate treatment and prevention efforts. Currently, clinicians and researchers must rely solely on the clinical interview of adolescents and their parents to ascertain diagnostic criteria for headache syndromes.

There is sparse literature on agreement between parent and adolescent reports of headache. One prior study of a small convenience sample of US children that assessed parent-child agreement regarding headache symptoms yielded higher levels of concordance for headaches of longer duration and for visual symptoms.¹⁵ Two of the 3 European studies of school-based samples that assessed headache symptoms found low levels of agreement between parent and child reports,^{16,17} whereas another study found that only 74% of parents were aware of their child's headaches, with greater awareness of migraine and tension-type headaches, in daughters, and in the presence of parental history of headache.¹⁸ None of the 5 prior population-based studies of US youth^{2,6,12,14,19} have assessed both parents and children.

Parent-child agreement for clinical disorders has perhaps been studied most widely in the field of psychiatry, which also relies solely on clinical assessment of criteria for diagnosis. Low levels of concordance between parent and child reports have been reported across disorders and across different diagnostic instruments in mental health research.^{20,21} Empirical studies have demonstrated that the most reliable and valid method of combining informant reports is to use information from either the parent or child in deriving diagnostic estimates because disagreement is generally based on differential awareness of parents and youth of emotional and behavioral symptoms, the extent to which they exceed normative thresholds, and their contextual influences. This research has also highlighted the extent to which parents may not be aware of internalizing symptoms or disorders such as anxiety and depression that may not be observable to others, particularly among adolescents. Therefore, the use of information from parents and youth is generally combined to assess diagnostic criteria.²⁰⁻²²

This study is the first nationally representative sample in the United States that included direct interviews of adolescents regarding the International Headache Society²³ symptoms of headaches, as well as parent reports of headaches in their adolescent offspring. The goal of the present study is to examine parent-adolescent agreement for headaches in a US population-based sample. The aims of this article are (1) to assess the overall concordance between parent and adolescent headache ratings; (2) to examine whether concordance in headache reports is associated with parental sex, adolescent sex, and adolescent age; and (3) to evaluate whether the type of headache and symptoms the adolescent experiences are associated with concordance of parent-adolescent report.

Methods

Sample

The National Comorbidity Survey-Adolescent Supplement is a nationally representative sample of 10 148 adolescents aged 13 to 18 years. The adolescent sample came from 2 sources of recruitment: 904 from households where an adult in the household participated in the prior study (National Comorbidity Survey-Replication) and 9244 from 320 schools throughout the United States. The background, measures, design, and clinical validity of the National Comorbidity Survey-Adolescent Supplement have been described in detail elsewhere.^{24–27} Recruitment and consent procedures were all approved by the Human Subjects Committees of Harvard Medical School and the University of Michigan. All adolescents were interviewed about their health using the World Health Organization's Composite International Diagnostic Interview, a structured face-to-face diagnostic interview administered by trained interviewers. Caregivers were given the Parent Self-Administered Questionnaire, which asked the caregiver about the adolescent's health and had a conditional response rate of 83.3%. A long version and short version of the Parent Self-Administered Questionnaire were administered, but only the long version asked the caregiver, "Has he/she ever had frequent or very bad headaches or migraine headaches?" about the adolescent's headaches, which reduced the sample to 6483.

Defining Headache Subtypes

Headaches were assessed using an interview of physical health conditions based on the US National Health Interview Survey.²⁸ Respondents were asked a lifetime headache screening question, "Have you ever had frequent or very bad headaches?" followed by a series of questions regarding headache symptoms during the past 12 months that assess the International Headache Society criteria for the most common headache subtypes. These questions were also used in the National Comorbidity Survey-Replication, as described in more detail by Saunders et al.²⁹ Four categories of headache are defined for this study: migraine without aura, migraine with aura, subthreshold migraine, and other headache.

Migraine without aura is defined using the International Headache Society's International Classification of Headache Disorders, Second Edition²³ criteria with the exception of the following criteria: (1) a minimum of 5 lifetime attacks or (2) aggravation by or causing avoidance of routine physical activity. Migraine with aura is defined as migraine with the presence of spots, lines, or heat waves and a partial loss of vision before the headache. Subthreshold migraine is defined as the International Headache Society criteria for migraine minus any one symptom. Finally, other headache captures those participants who endorsed headache but do not meet any of the above criteria. In addition, we divided the categories into those with chronic headache, defined as headache for more than 180 days per year, and those without chronic headache.

Table 1 shows the sociodemographic characteristics of the sample by headache group. The prevalence of headaches in this sample is higher in girls across most subtypes, especially for migraine without aura (11.3% in girls; 4.9% in boys). A majority of the sample was white, non-Hispanic, followed by black, non-Hispanic. Most parents had completed at least some college education and were married or cohabitating.

Other Characteristics of Parents and Adolescents

Other characteristics that were included in the evaluation of concordance included the specific symptoms of headaches, the gender of the caregiver, the gender of the child, and age of the child. Caregiver gender was defined from a question in the Parent Self-Administered Questionnaire about the respondent's relationship to the adolescent.

Statistical Analyses

Concordance of caregiver's report of adolescent headache and adolescent's report of headache was examined by age of the adolescent, sex of the adolescent, and sex of the caregiver. The sample size in the analyses of demographic correlates of agreement was smaller ($n = 6003$) than the total agreement because of missing information on the gender of the respondent that could not be determined because of multiple caregivers filling out the questionnaire at the same time ($n = 230$), missing information on the sex of the respondent ($n = 163$), and questionnaires in which the sex of the respondent could not be determined because the answer choice was not sex specific (ie, relationship to adolescent is "guardian not related, other relative, or other"; $n = 87$).

To evaluate the concordance of parent reports of adolescent headache with the adolescent reports about themselves, the sensitivity, specificity, area under the curve (AUC; the area under the receiver operating characteristic curve),³⁰ kappa (κ),³¹ and Yule's Q ³² results were obtained using SAS 9.2³³ and SUDAAN.³⁴ Adolescent report of headache was used as the gold standard when measuring sensitivity and specificity. Area under the curve, kappa, and Yule's Q are all statistical measures of agreement and overall diagnostic accuracy of the parent report compared with the adolescent report. Associations between parent report of headache and headache subtypes and specific headache symptoms were evaluated using odds ratios. Because of the weighting and clustering used in the National Comorbidity Survey-Adolescent Supplement design, the odds ratios from the logistic regression were computed using the Taylor series linearization method,³⁵ controlling for sex, race, parent education, age, and caregiver sex. Statistical significance was evaluated using a 2-sided design based on .05-level tests.

Results

Concordance

Of the 6339 caregiver and adolescent pairs who completed both the Parent Self-Administered Questionnaire and the Composite International Diagnostic Interview, 11% agreed regarding the presence of headaches and 68% agreed regarding the absence of headaches in the adolescent. Five percent of caregivers reported that the adolescent had headaches when the adolescent denied headaches, and 16% of caregivers denied headaches in their adolescent when the adolescent endorsed headaches. Overall, only 42% of parents of youth with headaches reported that their offspring had headaches, and only 59% of youth with full International Headache Society-defined migraine were accurately identified by the caregiver.

The results of the concordance analysis of the general headache probe are presented in Table 2. The overall kappa of agreement was 0.39, which is considered fair,³⁶ and the area under the curve was 0.67, which would be considered fair to poor predictive value beyond chance.³⁷

Table 3 shows the prevalence and concordance by the sex of the caregiver, sex of the adolescent, and age of the adolescent. Female caregivers were 2 times more likely than male caregivers to report adolescent headache (odds ratio = 2.0 [1.1–3.4]; $P = .01$). There was also a slight trend toward parents reporting more headache in male adolescents than in female adolescents (odds ratio = 1.2 [1.0–1.5]; $P = .03$). Although concordance was slightly greater for the 15- to 16-year-olds, there were no significant differences for parent-reported headache rates among the 3 age groups.

Diagnostic and Symptom-Level Predictors of Concordance

Table 4 presents the associations between headache subtypes and parent-adolescent agreement for headache. Although caregivers were not more likely to report headache when their offspring had migraine with aura compared with migraine without aura, there was an association between parental report and migraine when compared with those with subthreshold migraine. The likelihood of parents reporting headache also increased for all headache diagnostic groups when compared with the non-headache group.

The associations between headache features and agreement are shown in Table 5. The chronicity of the headaches and photophobia (increased sensitivity to light) or phonophobia (increased sensitivity to noise) increased the likelihood that the parent would report adolescent headache. Chronicity resulted in a 3-fold increase in reporting, and photophobia or phonophobia resulted in a 2-fold increase. In addition, parent report of headaches increased as the duration of headaches increased.

Discussion

The major findings of this study are that the prevalence rates of headache based solely on parental reports are likely to be a dramatic underestimate when compared with self-reported headaches in youth. Mothers/female caregivers are more likely to recognize headaches in their offspring than fathers/male caretakers, and caregivers are slightly more likely to report headaches in their male offspring. Clinical characteristics of adolescent headache that were associated with greater concordance included chronicity and longer duration, as well as the presence of photophobia or phonophobia.

These findings have important implications for population-based research on chronic conditions. Previous studies that have relied solely on parental or other informant reports have probably yielded underestimates of the prevalence of headache or migraine in the general population. For example, in the National Health Interview Survey, the prevalence of headaches in adolescents was 9.3% based on reports from 1 adult household member,¹² whereas the prevalence of headaches based on adolescent interview in the current study was 26.8%.

The underreporting of headache by parents in this study confirms previous studies of underestimation of emotional symptoms and disorders by parents compared with their adolescent offspring. One of the most common explanations given for discrepancies between adolescent and parent report in psychiatric symptoms is a lack of parent-youth communication.²² In general, the lack of awareness of adolescent emotional states has been attributed to the normative developmental process of adolescence that occurs as peers and others outside the nuclear family begin to assume greater roles as confidantes.^{38–41} Our finding that this lack of awareness may also extend to chronic physical conditions, particularly for symptoms that may not be clearly observable to others, has not been previously reported for headache.

The gender differences in reporting for this study have also been previously reported in studies of informant characteristics for psychiatric disorders.^{42,43} More accurate reports of headaches in female caregivers may be due in part to female caregivers spending more time with their children⁴⁴ and the increased tendency of adolescents to disclose information to their mothers more than their fathers.⁴²

Both our findings and those of previous studies reveal that headache concordance is greater for severe or chronic headaches and objective symptoms of headaches.^{15,18} Although headaches primarily consist of subjective symptoms, particularly pain, migraine headaches

are often accompanied by observable signs such as vomiting, and other symptoms, such as sensitivity to light and noise and pain being aggravated by routine physical activity, are more likely to affect behaviors. Adolescents who experience migraine may stop what they are doing in order to lie down, go into a dark room, and turn off the television or music to make the room quiet, and the pain they experience is often more severe than the pain that accompanies other types of headaches. Therefore, migraine may affect routine external behaviors that would be noticed by a caregiver more so than other headaches. This may also be the reason for increased reporting by parents when adolescents endorse photophobia or phonophobia with their headaches. These 2 symptoms of migraine could potentially have the biggest impact on behavior because of the need to retreat from light and noise.

Similar to the varying severity by diagnosis, adolescents who experience chronic headache (more than 180 days per year) and those who have headaches with a longer duration may experience more impairment that is observable to others. Parents may be more likely to notice their adolescent's headaches if they are occurring on more than half the days in a year or for longer durations of time with each headache.

Strengths and Limitations

This is the first study to examine parent-child concordance for headaches in a nationally representative sample of the United States that included reports by both parents and adolescents on the presence and absence of headaches. Adolescents were interviewed directly about their headache symptoms face-to-face, and the diagnostic criteria for International Headache Society-defined migraine were assessed in the interview. The information on headache symptoms and duration enhanced our ability to examine the concordance between parent and adolescent report based on differences between subtypes.

Several study limitations should be considered when interpreting these findings. First, the presence of headache and diagnosis of headache subtypes are based on retrospective recall, which makes the findings subject to potential recall bias. Second, although the adolescents were interviewed face-to-face about headache symptoms, caregiver information was based on a self-administered questionnaire that did not include specific symptoms of headaches. Third, no information was available regarding disability or impairment associated with headaches. Therefore, levels of concordance could not be compared by treatment seeking or disability. Fourth, we assumed that the adolescent report was accurate and compared parent reports against adolescent reports as the gold standard. However, it is possible that the parent report was actually valid in cases of disagreement. Although our collection of substantial information on the symptoms and characteristics that permitted application of International Headache Society headache subtypes makes adolescent overreporting less likely, our assumption that the adolescent interview was the gold standard may have been erroneous in some cases. Finally, our findings are based on a population survey of adolescents and may not extend to younger children or youth in clinical settings.

Implications and Future Directions

These findings have implications for caregivers, researchers, and clinicians. There is a clear lack of awareness on the part of caregivers of the extent to which their offspring suffer from headaches. The lack of recognition of headache is particularly important because of the significant impact of migraine and headaches on adolescents' educational progress and medical and physical morbidity.^{4-6,12,45,46} Efforts should be made to increase caregivers' awareness of the signs of headaches in adolescents, especially given the increasing prevalence of headaches during puberty.^{6,12,47} Researchers should also be aware of the low levels of parent-adolescent concordance for headaches when assessing the prevalence of headache in adolescent samples. Relying only on parent report could result in an

underestimation of the true prevalence and impact of adolescent headaches.⁴⁸ Finally, clinicians should be aware of the importance of direct assessment of the adolescent when ascertaining information about the adolescent's headache history. Systematic inquiry of both adolescents and their parents may provide a more comprehensive assessment of the full scope and impact of headache in youth. Such information is critical to effective treatment and prevention of the severe consequences of migraine.

Conclusions

Adolescent report is a far more sensitive measure of headaches than caregiver report. This finding suggests that prevalence estimates of headache in community surveys based on parent informants can underestimate the true prevalence of headache and migraine in the general population.

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Table 1

Sociodemographic Characteristics of the National Comorbidity Survey-Adolescent Supplement Parent Self-Administered Questionnaire Sample (n = 6483)

Sociodemographics	Category	Total	Migraine With Aura (n = 65), % (SE)	Migraine Without Aura (n = 480), % (SE)	Subthreshold Migraine (n = 115), % (SE)	Other Headache (n = 197), % (SE)	None (n = 5626), % (SE)
Sex	Male	3150	0.8 (0.2)	4.9 (0.5)	1.3 (0.4)	2.2 (0.4)	90.8 (0.8)
	Female	3333	0.9 (0.2)	11.3 (0.7)	2.4 (0.4)	4.1 (0.9)	81.3 (1.2)
Age-y	13–14	2611	0.8 (0.2)	7.7 (1.0)	1.3 (0.3)	3.5 (1.1)	86.8 (1.3)
	15–16	2528	0.9 (0.3)	7.6 (0.6)	2.6 (0.7)	3.5 (0.5)	85.5 (1.4)
	17–18	1344	1.1 (0.4)	9.5 (1.3)	1.2 (0.5)	1.7 (0.5)	86.5 (1.4)
	Non-Hispanic white	4257	0.9 (0.2)	8.5 (0.6)	2.2 (0.5)	2.3 (0.2)	86.2 (0.9)
Race	Non-Hispanic black	1097	0.6 (0.4)	7.3 (1.1)	1.2 (0.3)	4.3 (0.3)	86.6 (1.4)
	Hispanic	758	0.8 (0.4)	5.8 (1.2)	0.8 (0.4)	6.0 (2.5)	86.6 (2.7)
	Other	371	2.0 (0.9)	10.5 (3.5)	1.6 (0.7)	2.3 (1.0)	83.7 (3.3)
	Less than high school	746	0.9 (0.5)	8.0 (2.0)	2.6 (0.9)	2.7 (0.7)	85.7 (2.6)
Parental education	High school	1852	0.4 (0.2)	7.4 (0.8)	2.6 (0.8)	3.9 (0.6)	85.8 (1.2)
	Some college	1364	1.5 (0.6)	8.6 (1.2)	1.9 (0.8)	4.7 (1.8)	83.2 (2.5)
	College grad	2521	0.9 (0.2)	8.2 (1.1)	0.9 (0.2)	1.7 (0.3)	88.3 (1.2)
	Married/cohabiting	4602	2.0 (0.4)	8.5 (0.5)	2.0 (0.4)	2.4 (0.4)	86.3 (0.8)
Parental marital status	Previously married	1009	0.6 (0.3)	7.2 (1.4)	1.9 (0.6)	5.2 (2.2)	85.1 (2.4)
	Never married	308	0.4 (0.2)	7.6 (1.5)	1.0 (0.5)	3.7 (1.7)	87.3 (2.4)
	Metro	2645	1.3 (0.4)	85.0 (1.7)	2.4 (0.6)	3.1 (1.0)	85.0 (1.7)
Urbanicity	Other urban	2242	2.8 (0.4)	87.5 (0.8)	1.1 (0.3)	2.8 (0.4)	87.5 (0.8)
	Rural	1596	0.6 (0.2)	7.4 (1.1)	2.2 (0.6)	3.8 (0.7)	86.1 (1.9)
	IPL < 1.5	925	0.4 (0.2)	7.4 (1.1)	1.2 (0.6)	3.1 (0.7)	87.9 (1.3)
Income/poverty line (IPL)	1.5 ≤ IPL ≤ 3	1218	0.9 (0.4)	8.9 (1.2)	1.9 (0.7)	3.9 (1.0)	84.3 (1.5)
	3 < IPL ≤ 6	2139	0.9 (0.2)	8.5 (0.9)	1.8 (0.8)	2.2 (0.4)	86.5 (1.2)
	IPL > 6	2201	1.1 (0.4)	7.3 (0.8)	2.0 (0.5)	3.5 (1.2)	86.1 (1.5)

Table 2

Prevalence and Concordance of Parent and Adolescents on Severe Headaches/Migraine

Measure	% (SE)
Prevalence	
Parent	16.5 (0.70)
Adolescent	26.6 (0.90)
Sensitivity	0.42 (0.02)
Specificity	0.93 (0.01)
Kappa	0.39 (0.0002)
Positive predictive value	0.67 (0.02)
Negative predictive value	0.81 (0.01)
Area under the curve	0.67 (0.01)
Yule's Q	0.80 (0.0002)

Table 3
Prevalence and Concordance of Parent and Adolescent Report of Headache by Sex of Caregiver and Adolescent and Age of Adolescent

	Prevalence Parent Report	Prevalence Adolescent Report (Gold Standard)	Sensitivity	Specificity	Kappa	Positive Predictive Value	Negative Predictive Value	Area Under the Curve	Yule's Q
Male caregiver	9.9 (1.9)	26.3 (2.1)	0.62 (0.02)	0.97 (0.01)	0.32 (0.0007)	0.77 (0.07)	0.62 (0.02)	0.79 (0.02)	0.85 (0.0008)
Female caregiver	17.3 (0.9)	26.5 (1.1)	0.43 (0.02)	0.92 (0.05)	0.40 (0.0003)	0.66 (0.02)	0.82 (0.01)	0.68 (0.01)	0.80 (0.0003)
Male adolescent	15.8 (0.8)	21.4 (1.1)	0.44 (0.03)	0.92 (0.07)	0.41 (0.0004)	0.61 (0.04)	0.86 (0.09)	0.69 (0.01)	0.81 (0.0003)
Female adolescent	17.3 (1.0)	32.1 (1.3)	0.39 (0.03)	0.93 (0.07)	0.37 (0.0003)	0.73 (0.03)	0.76 (0.01)	0.66 (0.008)	0.80 (0.0004)
Adolescent age 13–14y	15.8 (1.3)	27.0 (1.4)	0.36 (0.03)	0.92 (0.01)	0.33 (0.0004)	0.63 (0.05)	0.80 (0.01)	0.66 (0.01)	0.74 (0.0005)
Adolescent age 15–16y	17.2 (1.0)	27.3 (1.8)	0.46 (0.03)	0.94 (0.08)	0.45 (0.0004)	0.73 (0.04)	0.82 (0.02)	0.68 (0.01)	0.85 (0.0003)
Adolescent age 17–18y	17.1 (1.8)	24.8 (2.0)	0.43 (0.04)	0.91 (0.01)	0.38 (0.0005)	0.62 (0.05)	0.83 (0.02)	0.67 (0.01)	0.78 (0.0006)

Values presented as estimate (SE).

Table 4

Associations Between Headache Subtypes in Adolescents and Parent Endorsement of Headache^a

	Versus Sub-Migraine			Versus Other Headache (Other HA)			Versus None			
	MO	MA	MO	MA	MO	Sub-Migraine	MA	MO	Sub-Migraine	OtherHA
All participants	1.5 (0.6–3.3)	3.9 (1.2–12.4)*	2.7 (1.5–4.9)**	5.3 (2.4–11.5)****	3.7 (2.2–6.0)****	1.4 (0.6–3.1)	16.3 (7.8–34.1)****	11.3 (8.8–14.4)****	4.2 (2.2–8.0)****	6.3 (7.8–34.1)****
Participants had headache last year	1.3 (0.5–3.1)	3.4 (1.0–11.7)*	2.7 (1.4–5.1)**	4.5 (2.0–10.0)***	3.5 (2.2–5.6)****	1.3 (0.6–3.0)	NA	NA	NA	NA

Data presented as odds ratio (95% confidence interval). MA, migraine with aura; MO, migraine without aura; Sub-Migraine, subthreshold migraine; NA, not applicable.

^a Controlled for sex, race, parent education, age, and parent sex.

* $P < .05$

** $P < .01$

*** $P < .001$

**** $P < .0001$

***** $P < .0001$

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Table 5

Associations Between Headache Symptoms and Parent Endorsement of Headache^a

	Chronicity ^b	Nausea/Vomiting	Photophobia/Phonophobia	Pulsating	Unilateral	Intensity	Aura
Adolescent who had headache, odds ratio (95% confidence interval)	2.8 (1.6–4.9) ***	1.2 (0.8–1.8)	2.2 (1.4–3.4) ***	1.1 (0.8–1.7)	1.2 (0.8–1.8)	1.4 (0.6–3.7)	0.9 (0.4–2.1)

^aControlled for headache group, sex, race, parent education, age, and parent sex.

^bAll categories are shown for lifetime headache except chronicity, which is for a 12-month headache.

*** $p < .001$.