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Complicated Grief and Associated Risk Factors Among Parents Following a Child's Death in the Pediatric Intensive Care Unit

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Objective: To investigate the extent of complicated grief symptoms and associated risk factors among parents whose child died in a pediatric intensive care unit.

Design: Cross-sectional survey conducted by mail and telephone.

Setting: Seven children's hospitals affiliated with the Collaborative Pediatric Critical Care Research Network from January 1, 2006, to June 30, 2008.

Participants: Two hundred sixty-one parents from 872 families whose child died in a pediatric intensive care unit 6 months earlier.

Main Exposure: Assessment of potential risk factors, including demographic and clinical variables, and parent psychosocial characteristics, such as attachment style, caregiving style, grief avoidance, and social support.

Main Outcome Measure: Parent report of complicated grief symptoms using the Inventory of Complicated Grief. Total scale range is from 0 to 76; scores of 30 or higher suggest complicated grief.

Results: Mean (SD) Inventory of Complicated Grief scores among parents were 33.7 (14.1). Fifty-nine percent of parents (95% confidence interval, 53%-65%) had scores of 30 or higher. Variables independently associated with higher symptom scores in multivariable analysis included being the biological mother or female guardian, trauma as the cause of death, greater attachment-related anxiety and attachment-related avoidance, and greater grief avoidance.

Conclusions: Parents who responded to our survey experienced a high level of complicated grief symptoms 6 months after their child's death in the pediatric intensive care unit. However, our estimate of the extent of complicated grief symptoms may be biased because of a high number of nonresponders. Better understanding of complicated grief and its risk factors among parents will allow those most vulnerable to receive professional bereavement support.

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ALTHOUGH THE DEATH OF A loved one is often highly stressful, most people eventually adjust to their loss. Some people, however, have complicated grief, a syndrome distinct from usual grief and other recognized mental disorders.[1-3] Symptoms of complicated grief include intense yearning for the deceased, a sense of disbelief regarding the death, anger and bitterness, intrusive and preoccupying thoughts of the deceased, avoidance of reminders of the loss, and difficulty moving on with life. The persistence of these symptoms for at least 6 months has been associated with poor mental and physical health outcomes and reduced quality of life.[4-7]

Most research on complicated grief has been conducted in elderly individuals following spousal loss.[1,4-6,8-16] Estimated prevalence rates for complicated grief among bereaved spouses range from 10% to 20%.[6,8,9] Identified risk factors include childhood adversities (eg, abuse),[10] childhood separation anxiety,[11] insecure attachment styles and marital quality,[12-14] lack of preparedness for the death,[8,14] and demographic characteristics (eg, sex, race).[5,15] Lack of social support has not consistently been shown to increase risk for complicated grief among elderly widows and widowers.[16,17] The prevalence and risk factors for complicated grief in other bereaved groups are less well studied partly because other types of loss are less common.

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Parents often have intense grief after the death of a child.[18-21] The intensity of parental grief has been attributed to the disruption in natural order that occurs when parents outlive their children, feelings of failure, and breakdown in family structure and its afforded stability.[22] In the United States, about 53 000 infants and children die annually.[23] More than 50% of these deaths occur among hospital inpatients, 80% following intensive care.[24,25] Death in the pediatric intensive care unit (PICU) is often unexpected by parents who are hoping for recovery with use of aggressive therapies.[20] Parents' preparedness for death may be less than in other clinical settings such as pediatric oncology or palliative care. Our objective was to investigate the extent of complicated grief symptoms and associated risk factors among parents whose child died in a PICU. Better understanding of parents' grief responses can guide strategies for bereavement support.

METHODS

DESIGN AND SETTING

The study was a cross-sectional survey conducted across 7 tertiary care children's hospitals affiliated with the Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network.[26] The study was approved by the institutional review board at each site.

STUDY POPULATION

The study included biological parents and legal guardians (collectively referred to hereafter as parents) of children who died in the PICU at a Collaborative Pediatric Critical Care Research Network site between January 1, 2006, and June 30, 2008. Medical records of the deceased children were reviewed to obtain the parents' contact information and primary language. Parents who did not speak English or Spanish were excluded.

DATA COLLECTION

Eligible parents were mailed closed-ended surveys in English or Spanish 6 months after their child's death. If completed surveys were not returned within 1 month, telephone contact was attempted to offer parents the option of completing the survey by telephone. If the household was successfully contacted by telephone but the survey was not completed, the parent was categorized as refusing to participate. If the household could not be contacted by telephone after 3 or more attempts, the parent was categorized as unable to locate.

MEASURES

Outcome Variable

The primary outcome variable was the extent of complicated grief symptoms as assessed by the Inventory of Complicated Grief (ICG).[27] The ICG is a 19-item instrument in which respondents report the frequency that they experience the cognitive, emotional, and behavioral states described in each item. Responses are reported on a 5-point scale ranging from 0 ("never") to 4 ("always"). Item responses are summed to obtain total scores ranging from 0 to 76. Higher scores indicate more complicated grief symptoms. Scores more than 25 have been associated with impaired general, mental, and physical health; poor social functioning; and bodily pain.[27] Scores of 30 or higher at least 6 months after a death have been used to indicate complicated grief.[28]

Risk Factor Variables

The potential risk factors of interest in this study were the parents' demographic characteristics and their children's clinical characteristics and the parents' attachment style, caregiving style, extent of grief avoidance, and social support. All assessments of risk factors were obtained by parent report.

Parents' demographic characteristics included age, sex, race/ethnicity, marital status, education, relationship to the deceased child, and number of surviving children. Parents selected their race and ethnicity from predefined lists. If ethnicity was described as Hispanic, the parent was categorized as being Hispanic regardless of race. Relationship to the child was categorized as biological mother, biological father, or other female or male guardian. Children's clinical characteristics included age, sex, and cause of death. Cause of death was categorized as cardiac, respiratory, malignancy, sepsis/multiple organ failure, neurologic, trauma, or other.

Parents' attachment style was assessed using the Relationship Scales Questionnaire.[29] The Relationship Scales Questionnaire is a 30-item instrument in which respondents rate the extent to which each item describes their characteristic style in close relationships. Each item is rated on a 5-point scale ranging from 1 ("not at all like me") to 5 ("very much like me"). Factor analysis with varimax rotation was performed to derive subscales for 2 underlying dimensions: attachment-related anxiety and attachment-related avoidance. Internal reliability of the derived subscales was assessed using the Cronbach α. Subscales were scored as the mean of the responses for the items included in the subscale. Scores for each subscale range from 1 to 5; higher subscale scores indicate more attachment-related anxiety or avoidance, respectively.

Parents' caregiving style was assessed using the Caregiving Questionnaire.[30] The Caregiving Questionnaire is a 32-item instrument in which respondents rate the extent to which each item describes their characteristic style of supporting, responding to, and caring for significant others. Each item is rated on a 6-point scale ranging from 1 ("not at all descriptive of me") to 6 ("very descriptive of me"). Two subscales are scored: responsive and compulsive caregiving.[31] Subscales are scored as the mean of the responses for the items included in the subscale. Scores for each subscale range from 1 to 6; higher subscale scores indicate more responsive or compulsive caregiving, respectively.

Parents' grief avoidance was assessed using the Grief Avoidance Questionnaire.[32] The Grief Avoidance Questionnaire is a 7-item instrument assessing 3 avoidance behaviors (ie, avoiding thinking about, talking about, and expressing feelings about the deceased) in 2 contexts (ie, with close family members and with close friends). The avoidance of thinking about the deceased is also phrased for respondents being alone. Respondents report the frequency that they had experienced each item in the past month on a 5-point scale ranging from 1 ("almost never") to 5 ("almost constantly"). Item responses are summed to obtain total scores ranging from 7 to 35. Higher scores indicate more grief avoidance.

Parents' social support was assessed using the Social Support Questionnaire–Short Form.[33] The Social Support Questionnaire–Short Form is a 6-item abbreviated version of the full Social Support Questionnaire.[34] For each item, respondents list the people that are available for help (ie, 0-9 people) in the manner described and rank their degree of satisfaction with that

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support on a 6-point scale ranging from 1 ("very dissatisfied") to 6 ("very satisfied"). Two subscales are scored: availability of social support and satisfaction with social support. Subscales are scored as the mean of the responses for the items included in the subscale. Scores for the availability subscale range from 0 to 9 and for the satisfaction subscale, from 1 to 6. Higher subscale scores indicate greater social support availability and satisfaction, respectively.

STATISTICAL ANALYSIS

The ICG score was analyzed as a continuous variable. The percentage of individuals with an ICG score of 30 or higher and associated 95% confidence interval are also summarized as a measure of complicated grief. For all survey measures, the score was calculated based on available data if at least 60% of the items in that measure were completed. For scores reflecting a sum, this was accomplished by multiplying the total sum by the number of questions in the measure divided by the number of questions answered, an approach equivalent to calculating the mean response for available data. If less than 60% of items were completed, the score was considered missing. Individuals were excluded from analysis if there was insufficient information to score the ICG or if no parent demographics were provided.

In univariable analyses, the mean and standard deviation of the outcome for each level of the categorical risk factors is described. For continuous risk factors, the linear relationship with the outcome using Pearson correlation coefficients (r) is described. Generalized estimating equations were used to assess the statistical significance of both univariable and multivariable associations. This approach accounts for clustering, or correlation, in responses when both of the child's parents completed surveys. Potential risk factors with a P value $<.25$ in univariable analyses were considered for inclusion in the multivariable model. The final model was determined using backward variable selection with a significance level to stay of .10. The effect estimates with 95% confidence intervals for the final model are described. Since the outcome is continuous, the generalized estimating equations results are analogous to those obtained from a linear regression model.

RESULTS

During the study period, 872 families were eligible to participate. One or both parents from 23% of families responded to the survey, 22% of families refused, and 55% could not be located. Of parent respondents, 79% completed the survey in English by mail, 14% in English by telephone, 5% in Spanish by mail, and 2% in Spanish by telephone. A total of 264 survey responses were collected; 3 were excluded from all analyses because of missing ICG score or parent demographics. There were 7 parents for whom the ICG was scored in the presence of missing data. Of these, 4 were missing 1 response, 1 was missing 2 responses, and 2 were missing 5 responses. The final analysis data set represents 261 survey responses from parents of 195 children.

Parent respondents were mean (SD) 37.2 (10.0) years of age; 69% were female and 31% male. Sixty-four percent were white; 16%, black; 16%, Hispanic; and 5%, other races. Seventy-one percent were married and 29%, not married; 39% had a college degree, 33% had some college, 23% had a high school degree, and 5% had less than a high school education. Sixty-three percent were the child's biological mother; 27%, the biological father; 6%, a female guardian; and 4%, a male guardian. For 15% of respondents, the deceased child was their only child. Children of respondents were mean (SD) 5.7 (6.7) years of age at time of death; 55% were male and 45%, female; and 26% died of cardiac causes; 16%, multiple organ failure/sepsis; 14%, neurologic causes; 13%, malignancy; 11%, respiratory failure; 7%, trauma; and 14%, other causes.

The mean (SD) ICG score was 33.7 (14.1) (range, 4-70) with 59% (95% confidence interval, 53%-65%) of parents having ICG scores of 30 or higher. Factor analysis of Relationship Scales Questionnaire responses identified 2 underlying dimensions corresponding to attachment-related anxiety (11 items) and attachment-related avoidance (7 items). Both of these subscales demonstrated acceptable reliability (Cronbach $\alpha=.88$ and .73, respectively). Mean (SD) scores for attachment-related anxiety and avoidance were 2.4 (0.9) (range, 1.0-5.0) and 3.0 (0.8) (range, 1.3-5.0), respectively. Mean (SD) Caregiving Questionnaire scores for responsive and compulsive caregiving were 4.4 (0.9) (range, 1.8-6.0) and 3.2 (0.8) (range, 1.1-5.6), respectively. The mean (SD) Grief Avoidance Questionnaire score was 12.9 (6.2) (range, 7-32). Mean (SD) Social Support Questionnaire–Short Form scores for social support availability and satisfaction were 3.2 (1.8) (range, 0.0-9.0) and 5.3 (0.9) (range, 2.0-6.0), respectively.

UNIVARIABLE ANALYSIS

The ICG scores were significantly higher for parents who were biological mothers or female guardians, who were not married, and who had less education (**Table 1**). The ICG scores were also significantly higher for parents whose child died of trauma than those whose child died of other causes. The ICG scores were unrelated to race/ethnicity, number of surviving children, sex of the deceased child, and age of the parent ($r=-0.11$; $P=.08$) or child ($r=0.04$; $P=.60$).

Correlations between ICG scores and other survey measures were weak to moderate with a range (in absolute value) from 0.16 to 0.47. The ICG scores were positively correlated with attachment-related anxiety ($r=0.47$; $P<.001$), attachment-related avoidance ($r=0.37$; $P<.001$), grief avoidance ($r=0.26$; $P<.001$), and compulsive caregiving ($r=0.17$; $P=.02$). The ICG scores were negatively correlated with responsive caregiving ($r=-0.21$; $P=.003$) and social support availability ($r=-0.20$; $P=.002$) and satisfaction ($r=-0.16$; $P=.03$).

MULTIVARIABLE ANALYSIS

Variables independently associated with higher ICG scores in multivariable analysis included being the biological mother or female guardian, trauma as the cause of death, greater attachment-related anxiety and avoidance, and greater grief avoidance (**Table 2**).

COMMENT

Parents who responded to our survey had a high level of complicated grief symptoms 6 months after their

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Table 1. Relationship Between ICG Scores and Parent and Child Characteristics in 261 Parents

	Sample Size	ICG Score, mean (SD)	*P* Value
Parent sex			.006
M	80	30.6 (13.5)	
F	179	34.8 (14.0)	
Race/ethnicity			.18
White	162	31.8 (13.7)	
Black	40	34.1 (13.5)	
Hispanic	41	37.0 (14.7)	
Other	12	38.3 (8.2)	
Marital status			.02
Married	182	32.0 (13.5)	
Not married	75	37.4 (14.6)	
Education			.02
<High school	12	40.2 (9.6)	
High school degree	60	37.1 (16.0)	
Some college	85	34.0 (13.6)	
College degree	100	30.0 (12.5)	
Relationship to deceased child			.02
Biological mother	163	34.9 (14.1)	
Biological father	70	31.3 (13.6)	
Other female guardian	16	34.1 (13.9)	
Other male guardian	10	25.5 (12.4)	
No. of other children			.90
None	39	34.2 (14.4)	
1	84	34.1 (13.6)	
2	69	33.9 (13.5)	
≥3	65	31.9 (15.0)	
Child sex			.62
M	139	34.0 (14.2)	
F	121	33.2 (14.0)	
Cause of death			.002[a]
Cardiac	67	32.5 (13.7)	
Sepsis/multiple organ failure	41	32.8 (12.4)	
Neurologic	32	32.6 (14.7)	
Malignancy	29	29.7 (13.3)	
Respiratory	29	34.9 (15.7)	
Trauma	17	42.5 (12.9)	
Other	34	33.8 (14.4)	

Abbreviation: ICG, Inventory of Complicated Grief.
[a] *P* value for cause of death reflects comparison of trauma vs all others combined.

Table 2. Variables Independently Associated With ICG Scores in 241 Parents

Variable	Effect (95% CI)	*P* Value
Relationship to child		.05
Biological mother	1 [Reference]	
Biological father	−2.9 (−5.9 to 0.1)	
Other female guardian	2.3 (−3.5 to 8.0)	
Other male guardian	−6.7 (−12.7 to −0.7)	
Trauma cause of death	9.6 (3.0 to 16.3)	.005
Attachment-related anxiety (RSQ)	4.6 (2.8 to 6.5)	<.001
Attachment-related avoidance (RSQ)	3.1 (1.0 to 5.1)	.003
Grief avoidance score (GAQ)	0.31 (0.04 to 0.58)	.02

Abbreviations: CI, confidence interval; GAQ, Grief Avoidance Questionnaire; ICG, Inventory of Complicated Grief; RSQ, Relationship Scales Questionnaire.

child's death in the PICU. Fifty-nine percent of parents had ICG scores of a magnitude used to indicate complicated grief in prior research.[28] These findings must be interpreted with caution, however, because parents from only 23% of families responded to our survey. Respondents may have been those parents having the greatest difficulty adjusting to their child's death. In 2009, a diagnostic algorithm for complicated grief was proposed, and inclusion of the disorder in the forthcoming *Diagnostic and Statistical Manual of Mental Disorders* (*Fifth Edition*) has been suggested.[1] Although our assessment method did not allow for a formal diagnosis of complicated grief based on these criteria, the severity of symptoms reported by our survey respondents suggests that some parents are at risk for persistent distress and dysfunction following their child's death in the PICU.

Few studies have investigated complicated grief among bereaved parents,[35-37] and to our knowledge, none have investigated complicated grief among parents whose children died in PICUs. Dyregrov et al[35] conducted a cross-sectional survey in Norway among 232 parents identified from the national police register of suicide, accident, and sudden infant death syndrome and found that 78% of those bereaved by suicide or accident and 57% bereaved by sudden infant death syndrome had a high level of complicated grief symptoms (ICG scores >25) 18 months after the loss. Wijngaards-de Meij et al[36] conducted a longitudinal survey of 219 Dutch couples identified from children's obituary notices. Mean (SD) ICG scores transformed to a scale of 0 to 100 were 45.2 (19.8) at 6 months, 43.0 (18.7) at 13 months, and 41.5 (18.2) at 20 months indicating a high level of complicated grief symptoms over this period. Keesee et al[37] surveyed 157 parents who were recruited up to 40 years after their child's death from 2 community support groups in the southeastern United States and the Internet; ICG scores were inversely related to time since the loss. Li et al,[38] using data from large national registries in Denmark, found increased risk of first psychiatric hospitalization among bereaved parents, most pronounced in the first year, but extending for 5 years after the death.

Demographic and clinical risk factors for complicated grief symptoms identified by multivariable analysis among parents in our study included being the biological mother or female guardian and trauma as the cause of death. Lower education and being unmarried were related to complicated grief symptoms in univariable analysis only. These findings are consistent with prior studies that found female sex,[5,35] cause and unexpectedness of death (eg, traumatic or violent death),[8,15,36,37] and less education[15] to be associated with complicated grief and suggest that single parenthood may also play a role. Our findings showed no relationship between complicated grief symptoms and number of surviving children, although other researchers have suggested that additional children in the household may be a protective factor.[35,36]

Grief theorists have proposed that individual differences in adjustment to loss can be viewed from the perspective of attachment theory.[3,39] Attachment refers to an affectional bond between an individual and an attachment figure through which the individual seeks safety, security, and support. Mental representations of

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early attachment bonds (eg, infant-parent bonds) form the basis of one's general attachment style in close relationships. Two underlying dimensions to attachment are anxiety and avoidance.[40] Attachment-related anxiety reflects the extent to which one worries that others will be unavailable in times of need. People with high attachment anxiety typically have a very dependent relationship style and handle stress poorly. As such, people with high attachment anxiety have been considered at risk for poor bereavement outcomes. Attachment-related avoidance reflects the extent to which one feels uncomfortable relying on others or being relied on. People with high attachment avoidance strive to maintain autonomy and emotional distance; these characteristics potentially facilitate adaptation to loss. Our findings support the theoretical view that high attachment-related anxiety is a risk factor for severe grief symptoms. In contrast to theoretical views, our findings also suggest that high attachment-related avoidance is associated with more severe grief. Wijngaards-de Meij et al[41] reported a similar association between attachment-related avoidance and parental grief. These researchers have suggested that avoidance functions inadequately as a defense mechanism for bereaved parents because of the extreme nature of the loss.

Caregiving is the complement of the attachment system.[30] Caregiving behaviors (eg, behaviors intended to provide safety and security to others) mirror attachment behaviors (eg, behaviors intended to attain safety and security from others). Responsive caregiving is characterized by accessibility, sensitivity, and cooperation, whereas compulsive caregiving is characterized by overinvolvement and control. For parents, the death of a child represents loss of a caregiving relationship; however, to our knowledge, the association between caregiving style and parental grief has not been previously studied. Although less responsive and more compulsive caregiving were associated with a higher degree of complicated grief symptoms in univariable analysis, caregiving styles were not independent predictors in multivariable analysis. This is likely due in part to the interrelationships between caregiving and attachment.

Grief theorists have also proposed that adjustment involves some degree of grief avoidance as the bereaved oscillate between confronting painful emotions and defensive exclusion of the painful recognition of the loss.[42] Among those with complicated grief, however, grief-related avoidance can be excessive and impairing. In a study of 128 adult patients being treated for complicated grief disorder, the extent that patients avoided places, things, and activities that reminded them of their loss and death-related situations that evoked sympathy correlated with ICG scores.[43] Similarly, our findings suggest that excessive grief avoidance is related to complicated grief. Rather than a risk factor, excessive grief avoidance may be a component of complicated grief. Research also suggests that excessive rumination over the deceased may contribute to poor bereavement outcomes.[32]

Social support availability and satisfaction were not associated with the extent of parents' complicated grief symptoms in multivariable analysis. This finding is consistent with research conducted among elderly widows by Stroebe et al,[17] who found no evidence that social support had a buffering or recovery effect on bereavement. However, Kreicbergs et al[44] conducted a cross-sectional survey among 449 Swedish parents identified from national registries 4 to 9 years after their child's death of cancer and found that those reporting greater social support during and after the child's illness were more likely to have worked through their grief. Our findings suggest that the support of family and friends may be inadequate to ameliorate complicated grief symptoms among parents 6 months after their child's death.

Limitations of this study include the high percentage of potential participants who either refused or could not be located. The low response rate is typical of surveys of bereaved individuals and may be because of high levels of distress during bereavement and the added burden that research participation may impose. Characteristics of nonrespondents are unknown since medical records were reviewed for parent contact information and primary language only and all data were collected by self-report. Additionally, although the scales used in this study have previously been validated as individual measures, their validity when used together has not been established. Associations between scales may represent collinear rather than predictive relationships. Ideally, potential risk factors for complicated grief should be assessed prior to the child's death because the death experience itself may affect parents' responses to some survey measures. Strengths of this study include the racial, ethnic, and geographic diversity of respondents, which increases the generalizability of our findings.

In conclusion, parents who responded to our survey had a high level of complicated grief symptoms 6 months after their child's death in the PICU. Risk factors include demographic and clinical variables as well as psychological variables related to the attachment system. Better understanding of the prevalence and risk factors for complicated grief among parents will allow those most vulnerable to maladaptive grief responses to receive professional bereavement support. Further research regarding change in complicated grief symptoms over time and their relationship to long-term parent and family outcomes is needed.

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Author Contributions: Dr Meert has had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* Meert, Donaldson, Harrison, Anand, Carcillo, Dean, Willson, Nicholson, and Shear. *Acquisition of data:* Meert, Newth, Berger, Zimmerman, Anand, Carcillo, and Dean. *Analysis and interpretation of data:* Meert, Donaldson, Dean, and Nicholson. *Drafting of the manuscript:* Meert, Dean, and Nicholson. *Critical revision of the manuscript for important intellectual content:* Meert, Donaldson, Newth, Harrison, Berger, Zimmerman, Anand, Carcillo, Dean, Willson, Nicholson, and Shear. *Statistical analysis:* Meert, Donaldson, and Dean. *Obtained funding:* Meert, Newth, Harrison, Zimmerman, Anand, Carcillo, Dean, and Nicholson. *Administrative, technical, and material support:* Meert, Berger, Zimmerman, and Dean. *Study supervision:* Meert, Berger, Dean, and Nicholson.

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Announcement

The *Archives* is introducing a rolling theme issue on comparative effectiveness research for the care of children and adolescents. We are interested in comparative effectiveness research across the spectrum of care that child health care providers deliver. Priority will be given to studies that use rigorous methodological designs, are generalizable well beyond an individual institution's walls, and are real-world effectiveness studies. Please consult our Web site at http://www.archpediatrics.com for instructions on manuscript preparation and submission.

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