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East Holly Avenue Box 56 • Pitman, NJ 08071-0056
(856) 256-2300 • FAX (856) 589-7463 • E-mail: pnjrnl@ajj.com • www.pediatricnursing.net

Subscription rate: Personal \$52 per year. Institutional \$80 per year. \$30 additional postage (per year) outside U.S. Single copy \$15.

Claims for missing issues: Claims for missing issues must be submitted within 4 months (6 months international) of the publication date.

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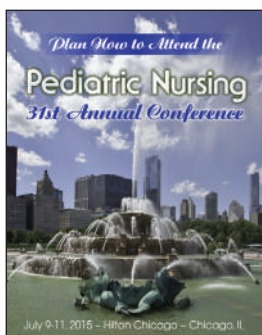
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(ISSN 0097-9805)

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From the Editor

Judy A. Rollins, PhD, RN

Some Thoughts about Empathy

Ever since the Columbine shooting in 1999, Americans have become increasingly concerned about such horrific events and the reasons behind them. Often cited reasons include mental illness, the availability of guns, or some fundamental differences in children and the stresses they endure today.

Research indicates links between school violence and bullying. In a study of more than 15,000 students who participated in the Health Behavior in School-Aged Children (HBSC) survey for grades 6 through 10, Nansel, Overpeck, Haynie, Ruan, and Scheidt (2003) reported that victims are more likely than children who have never been bullied to feel that violence is a solution to their problems. Children who bully or are bullied are more likely to be involved in one or more of the four violence-related behaviors: 1) carrying a weapon in the last 30 days, 2) carrying a weapon in school in the last 30 days, 3) frequent fighting during the last year, and 4) sustaining an injury during the last year from a fight that required medical care.

The youths most likely to carry a weapon said they bullied others in or away from school or were being bullied away from school. Both boys and girls who bully are more likely to be engaged in frequent fighting and injured in a fight, which is also true for boys who are bullied away from school.

Surveys indicate that bullying is decreasing in schools, likely due to interventions and an increased awareness of the problem (Zuckerman, Bushman, & Pedersen, 2012). Yet, the problem has not gone away. According to a recent report published by the Hazelden Foundation (Limber, Olweus, & Luxenberg, 2013), 16% of students report being bullied, while 7% report bullying others. Fortunately, with increasing grade level, the percentage of students who report being bullied decreases steadily, with a high of 22% in grades 3 and

4, to a low of 9% by grade 12. However, particularly disturbing is the finding that for 24% of students who are bullied, the bullying continues for several years or longer.

Lack of Empathy

Some bullying intervention programs are built on the notion that children who bully lack empathy and that developing empathy is the key to prevention. *Roots of Empathy*, an innovative evidence-based classroom program that increases empathy through visits by a neighborhood infant and parent every three weeks over the school year, has shown significant effect in reducing levels of aggression among schoolchildren (Roots of Empathy, n.d.).

Brain research indicates that some children who bully do not lack empathy, but that their brains empathize differently (Decety, Michalska, Akitsuki, & Lahey, 2009). They compared fMRI scans of eight boys 16 to 18 years of age with aggressive conduct disorder to a control group of adolescent boys with no unusual signs of aggression. The boys in both groups viewed video scenes of people accidentally hurting themselves, such as when a heavy bowl was dropped on their hands, and intentionally, such as when a person stepped on another's foot. For the non-aggressive boys, the expected parts of the brains signaled that the boys felt empathy for the people in pain. However, the scans of the aggressive boys who had signaled empathy toward pain associated that pain empathy with pleasure in the reward centers of the brain.

The researchers concluded that children who bully do not lack empathy, but instead, associate the pain of their victims as a positive feeling. Findings suggest that the abusive behavior of bullies feeds their brains with a feeling of reward. Thus, while they are empathetic, they are not empathetic in a way that causes remorse.

Troubling Trends

The issue of lack of empathy has much greater implications than those associated with bullying and violence. Children in general are less empathetic today than in the past. A meta-analysis of American college students ($N = 13,737$) found a 48% decrease in empathic concern and 34% decrease in perspective taking since 1979 (Konrath, O'Brien, & Hsing, 2011). Americans born in the 1980s or later showed the lowest level of empathy, similar to those born in the 1910s and 1920s. This finding held true across gender, race, and educational backgrounds. The researchers also note that declines in perspective taking and empathic concern are relatively recent phenomena and are most pronounced in samples from after 2000.

Accompanying this decline in empathy was a rise in self-esteem, individualism, and narcissism (Twenge, Konrath, Foster, Campbell, & Bushman, 2008). Nationally representative samples of high school and college students show that values have shifted toward extrinsic (money, fame, and image) concerns and away from intrinsic (community, affiliation) concerns. The negative consequences of these trends include lower empathy, less concern for others, and less civic engagement (e.g., interest in social issues, government, and politics) (Twenge, 2013).

Konrath (2013) suggests possible causes or contributing factors of this change in empathy over time:

- Changes in family settings and practices, such as smaller families and parenting styles.
- Changes in economic conditions and education environments, such as the rise of the self-esteem movement in the 1980s.
- Changes in the media/social environment seen in the 1980s with increased TV watching, video-games, computers, and in the 2000s, the rise of social networking.

Implications for Nursing

To address bullying directly, many prevention and intervention programs are available that strive to change the culture supporting bullying behavior. Nurses are frequently involved in implementing such bullying programs. As with any other intervention, careful attention is needed in the selection process to ensure that program content is evidence-based. Nurses also need to continue to advocate for children's mental health issues, including appropriate care for the child and family.

Perhaps because of our unique access to children and families, looking at the troubling trends, we can see where we, as nurses, might make the greatest impact. Twenge and colleagues (2008) and Konrath (2013) are not the first or only researchers who have pointed out the potential downside – lack of empathy, sense of entitlement – of an emphasis on self-esteem above all else. Through anticipatory guidance for parents, as well as sound guidance when problems arise, we can stress the need for balance

when promoting self-esteem. We can let parents know that the obesity epidemic is not the only reason to limit TV viewing and other electronic use. We also can design parenting programs that strike a balance in promoting the development of truly caring as well as confident children.

The time has come to consider a broader notion of culture change beyond that of the school to address the complex challenges of empathy that we as a society face. Through research and attention to the contributing factors, we can help create a culture of caring, one in which we all would choose to live. ■■■

References

- Decety, J., Michalska, K., Akitsuki, Y., & Lahey, B. (2009). Atypical empathic responses in adolescents with aggressive conduct disorder: A functional MRI investigation. *Biological Psychology, 80*(2), 203. doi:10.1016/j.biopsycho.2008.09.004
- Konrath, S. (2013, May). Empathy: Across time and across the world. *Roots of Empathy Research Symposium 2013 proceedings*. Retrieved from http://www.rootsofempathy.org/images/stories/content/2013_research_symposium_proceedings.pdf
- Konrath, S., O'Brien, E., & Hsing, C. (2011). Changes in dispositional empathy in American college students over time: A meta-analysis. *Personality and Social Psychology Review, 15*(2), 180-198.
- Limber, S., Olweus, D., & Luxenberg, H. (2013). *Bullying in U.S. schools*. Retrieved from <http://www.violencepreventionworks.org/public/index.page>
- Nansel, T., Overpeck, M., Haynie, D., Ruan, W., & Scheidt, P. (2003). Relationships between bullying and violence among U.S. youth. *Archives of Pediatric and Adolescent Medicine, 157*, 348-353.
- Roots of Empathy. (n.d.). *About our program*. Retrieved from <http://www.rootsofempathy.org/en/what-we-do.html>
- Twenge, J. (2013). The evidence for Generation Me and against Generation We. *Emerging Adulthood, 1*(1), 11-16.
- Twenge, J., Konrath, S., Foster, J., Campbell, W., & Bushman, B. (2008). Egos inflating over time: A cross-temporal Meta-analysis of the narcissistic personality inventory. *Journal of Personality, 76*, 875-902.
- Zuckerman, D., Bushman, S., & Pedersen, S. (2012). *Bullying and violence*. Retrieved from <http://center4research.org/violence-risky-behavior/z-other-violence/bullying-and-violence>

Evidence-Based Interventions For Neonatal Abstinence Syndrome

Nancy J. MacMullen, Laura A. Dulski, and Paul Blobaum

Neonatal abstinence syndrome (NAS) is a group of similar behavioral and physiological signs and symptoms in the neonate caused by withdrawal from various pharmacologic agents (Hamdan, 2010). The presentation of the syndrome is unpredictable, with individual neonates displaying different symptoms and symptom severity over time (Jansson, 2008). Depending upon the etiology, type of drug, the severity of the withdrawal, and the age of the neonate, care may be provided in the NICU, the obstetrical floor, or the pediatric unit. Other hospital units may be used depending upon the institution's preference. Neonates with NAS require specialized neonatal/pediatric nursing care based on the best evidence obtained from the literature and global benchmarking of best practices. To assist with translating research into practice, the objective of this article is to identify best nursing practice by systematically and critically reviewing the literature and expert guidelines on the topic.

Epidemiology

Maternal Incidence

Abuse of illicit and prescription drugs is a worldwide problem. In 2013, the United Nations Office on

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This review aimed to determine best nursing practice by systematically and critically reviewing the appropriate literature and expert guidelines. Using keywords and literature databases, over 480 journal titles were reviewed. Twenty-four articles and three expert guidelines were chosen. The majority of articles selected as evidence were Level IV – opinions of respected authorities based on clinical experiences, descriptive studies, case reports, or reports of experts. Two articles were Level I-II – experimental studies. Results of the review showed that traditional supportive interventions also have a body of evidence for their use. Although there is much research regarding neonatal abstinence syndrome (NAS), the majority of future research needs to be at a higher level of evidence. Nursing applications include obtaining evidence for best practice through diligent searches of the literature and expert guidelines.

Drugs and Crime (UNODC) reported that approximately 3.6% to 6.9% of the world's population 15 to 64 years of age abused illicit drugs at least once in the previous year (UNODC, 2013). In the United States, 5.9% of pregnant women 15 to 44 years of age used illicit drugs during the past month (Substance Abuse and Mental Health Administration [SAMHSA], 2012).

Infant/Neonatal Incidence

In the United States, approximately 225,000 infants yearly are exposed to illicit substances (Keegan, Parva, Finnegan, Gerson, & Belden, 2014). The prevalence of prenatally exposed newborns to one or more illicit drugs averages approximately 5.5%, with a range of 1.3% to 50% (Wang, 2014). Greater than 75% of infants exposed to drugs have major medical problems, compared with 27% of unexposed infants. Seventeen percent of drug-exposed versus 6% of unexposed babies are delivered prematurely (Huestis & Choo, 2002).

Cost

In addition to the personal costs in relationships, health, and the future development of neonates with NAS, there is a financial cost as well. It is common for neonates with NAS to

experience longer stays in the hospital than NAS-free neonates (Oei & Liu, 2007). Data from the AHRQ Healthcare Cost and Utilization Project (HCUP) Nationwide Inpatient Sample (2009) show that aggregate charges for substance-related disorders in the age category of less than one year were over 96 million dollars (\$96,440,575). The cost of keeping a drug-exposed child in a neonatal unit is estimated at \$2,700 per child per day (Cooper, 2004).

Etiology

There are two major types of NAS (Hamdan, 2010). The more recognized type is prenatal NAS, which is due to prenatal maternal use of substances. The abuse may result in withdrawal symptoms in the neonate once the placental access to the substance is no longer available. Drugs commonly implicated in prenatal NAS are opiates, barbiturates, cocaine, sedatives, ethanol, marijuana, and nicotine (Davison, Worsley, & Husband, 2007; Wang, 2010). Postnatal NAS results when an abrupt discontinuation of analgesia, such as Fentanyl or morphine, occurs usually after prolonged drug exposure for post-procedure pain management and/or sedation (Hamdan, 2010). The focus of this article is on prenatal NAS.

Pathophysiology

Drugs are transferred from the mother to the fetus via the placenta. Huestis and Choo (2002) describe the mechanisms responsible for the transfer: active transport (requires energy to move fluids into the cell), passive diffusion (requires no energy for movement), and pinocytosis (moves fluids by invagination of cell membrane). The authors also report that the ease of transport depends upon the size of the drug molecule, its lipophilicity, the pKa (acid ionization constant) of the compound and the pH of the blood. At delivery, the transplacental passage of the drug is interrupted, resulting in the development of a withdrawal syndrome in the neonate (Oei & Liu, 2007). The pathophysiology and mechanisms of withdrawal are poorly understood (Jansson, 2008). It is theorized that withdrawal can cause molecular and cellular alterations that produce systemic, behavioral, and cognitive symptoms (Wang, 2010).

Effects of Drugs On the Neonate

Symptoms and length of withdrawal vary according to the amount and type of drug used. For example, cocaine withdrawal occurs over a short period of time, whereas opiates can produce a longer and more threatening withdrawal (Greene & Goodman, 2003).

The effect of drugs on body systems is also influenced by the type of drug, the combination of drugs, the amount and frequency of use, the trimester in which the drug is used, the timing of withdrawal, and the genetic susceptibility of the fetus/neonate (Oei & Lui, 2007; Sun, 2004). Withdrawal symptoms relate to the type of drug ingested (see Table 1) (Davison et al., 2007; Hamdan, 2010; Huestis & Choo, 2002; Oei & Lui, 2007; Wang, 2010).

Medical Management

Medical management is aimed at treating the symptoms of withdrawal. Standardization of treatment is difficult because symptoms of withdrawal vary with each infant (Beauman, 2005). There is also a lack of double-blind controlled studies (Winklbaur et al., 2008). Most studies recommend matching the drug used to treat withdrawal to the type of drug abused (Beauman, 2005). For example, opiates

Table 1.
Effects of Drug Withdrawal on the Neonate

Drug(s)	Symptoms of Withdrawal
Opioids	Hyperirritability GI dysfunctions: Excessive sucking, poor feeding, regurgitation, diarrhea Tremors High-pitched cry Increased muscle tone Seizures Nasal congestion Hyperthermia Tachypnea
Cocaine	No significant withdrawal symptoms
Benzodiazapines	Few infants have withdrawal syndrome
Cannabis/marijuana	Jitteriness Tremors Impaired sleeping
Alcohol	Hyperactivity Central nervous system (CNS) dysfunction Fetal alcohol syndrome (FAS) Jitteriness Irritability Hyperreflexia Hypertonia Poor suck Tremors Seizures Poor sleep patterns Hyperphagia Diaphoresis
Selective Serotonin Reuptake Inhibitors (SSRIs)	Jitteriness Respiratory distress Sleep disturbance

should be given to the neonate if withdrawing from opiates (Kuschel, 2007; Osborn, Jeffrey, & Cole, 2005; Winklbaur et al., 2008). Expert guidelines formulated by the American Academy of Pediatrics Committee on Drugs (2012), Substance Abuse and Mental Health Services (2005) guidelines for medication-assisted treatment for opioid addiction, and the Western Australian Centre for Evidence-Based Nursing and Midwifery (2007) concur with these recommendations.

The Nursing Challenge

A number of nursing interventions are used for providing care to the neonate/infant with NAS. Many interventions are not based on a systematic review of the evidence presented in the literature, but rather, on tradition. The interventions seemed to work, so they were incorporated into practice. As research into NAS increased, tangible evidence as to best practice emerged. A thorough review

of nursing and medical literature is essential to determine if current nursing practice matches the recommendations found in the literature. Consultation with practice experts will also identify best practices.

Process of Literature Review

In consultation with a medical librarian, a systematic review of the literature was conducted using CINAHL and Medline/PubMed. Key words used in the search were "neonatal abstinence syndrome," "drug withdrawal," "nursing care," "nursing interventions," "newborns," and "neonates." MESH and CINAHL subject headings included "neonatal abstinence syndrome," "nursing," "newborns," and "substance withdrawal syndrome." Journal articles chosen for inclusion in the literature search had to meet the following criteria: topics had to focus on nursing

interventions for NAS; literature reviewed had to be international; and except for classic articles, the literature could be no older than 10 years. In addition, professional nursing and medical websites were used for the latest nursing, medical, and patient education information. National guidelines and systematic reviews were also consulted by searching the Health Services/Technology Assessment Texts (HSTAT), Cochrane Systematic Re-

views, and Joanna Briggs Institute databases. Topics reviewed included supportive interventions, breastfeeding, and NAS scoring systems. Over 480 publications were reviewed. Synthesis of the articles was accomplished through the use of a table that contained the title, author(s), journal particulars, and a content abstract. Specific levels of evidence were used for categorizing the quality of articles for the review (see Table 2).

Level of Evidence

The level of evidence for a systematic review ranges from Level I-II to Level IV (Wright, Brand, Dunn, & Spindler, 2007). Most nursing articles selected for this review were case reports/observational studies (Level IV). Seven studies were retrospective cohort studies (Level III). Two research articles reviewed were clinical trials with or without randomiza-

Table 2.
Systematic Review

Author	Title	Document: Journal, Guideline, Chapter	Type of Study/Design	Level of Evidence	Intervention(s)
American Academy of Pediatrics Committee on Drugs (2012)	Neonatal Drug Withdrawal	<i>Pediatrics</i> , 101(6), e540-e560	Expert opinion	IV	Initial treatment: Supportive-swaddling, nutritional support, observation of sleeping habits. NAS scoring system. Pharmacotherapy with drug of same class as that of drug abused.
Abdel-Latif et al. (2006)	Effects of Breast Milk on the Severity and Outcome of Neonatal Abstinence Syndrome among Infants of Drug-Dependent Mothers	<i>Pediatrics</i> , 117(6), e1163-e1169	Retrospective chart review	III	Breastfeeding.
Abrahams et al. (2007)	Rooming-In Compared with Standard Care for Newborns of Mothers Using Methadone or Heroin	<i>Canadian Family Physician</i> , 53(10), 1722-1730	Retrospective cohort study	III	Rooming-in.
Agency for Healthcare Research and Quality (AHRQ) (2010)	Guidelines for Breastfeeding and the Drug-Dependent Woman	U.S. Department of Health and Human Services	Guideline summary by consensus of committee of experts	IV	Breastfeeding with careful evaluation of maternal and infant substance abuse and substance treatment histories before initiation.
Ballard (2002)	Treatment of Neonatal Abstinence Syndrome with Breast Milk Containing Methadone	<i>Journal of Perinatal Neonatal Nursing</i> , 15(4), 76-85	Case series	IV	NAS scoring system. Breastfeeding, if no contraindications. Swaddling, low-light, low noise, gentle holding. Pharmacotherapy as needed.
Beauman (2005)	Identification and Management of Neonatal Abstinence Syndrome	<i>Journal of Infusion Nursing</i> , 28(3), 159-167	Case series	IV	Nutritional support. Sucrose pacifier for pain relief, dark, quiet environment, Clear dressings. Positioning in a supine position. Pharmacotherapy.
Curet & His (2002)	Drug Abuse During Pregnancy	<i>Clinical Obstetrics and Gynecology</i> , 45(1), 73-88	Case series	IV	Swaddling, quiet, dark room, nutritional support, pharmacotherapy.
D'Apolito & Hepworth (2001)	Prominence of Withdrawal Symptoms in Polydrug-Exposed Infants	<i>Journal of Perinatal Neonatal Nursing</i> , 14(4), 46-60	Secondary analysis	III	Swaddling, quiet, environment, gentle awakening, non-nutritive sucking.

continued on next page

Table 2. (continued)
Systematic Review

Author	Title	Document: Journal, Guideline, Chapter	Type of Study/Design	Level of Evidence	Intervention(s)
Dodge, Brady, & Maguire (2006)	Initiation of a Nurse-Developed Interdisciplinary Plan of Care for Opiate Addiction in Pregnant Women and Their Infants	<i>International Journal of Childbirth Education</i> , 21(2), 21-24	Case series	IV	Low lighting, decreased noise level, limited stimulation, rooming-in, decreased noise level, music therapy, cuddlers.
Fraser, Barnes, Biggs, & Kain (2007)	Caring, Chaos and the Vulnerable Family: Experiences in Caring for Newborns of Drug-Dependent Parents	<i>International Journal of Nursing Studies</i> , 44, 1363-1370	Interpretive methods (descriptive study)	III	Cuddlers.
Greene & Goodman (2003)	Neonatal Abstinence Syndrome: Strategies for Care of the Drug-Exposed Infant	<i>Neonatal Network</i> , 22(4), 15-25	Case series	IV	Quiet environment, non-nutritive sucking, vestibular stimulation, swaddling, minimal handling.
Jambert-Gray, Lucas, & Hall (2009)	Methadone-Treated Mothers: Pregnancy and Breast Feeding	<i>British Journal of Midwifery</i> , 17(10), 654-657	Case series	IV	Breastfeeding, rooming-in.
Jansson et al. (2008)	Methadone Maintenance and Breastfeeding in the Neonatal Period	<i>Pediatrics</i> , 121(1), 106-114	Non-randomized clinical trial	I-II	Breastfeeding for methadone-maintained women.
Kuschel (2007)	Managing Drug Withdrawal in the Newborn Infant	<i>Seminars in Fetal & Neonatal Medicine</i> , 12(2), 127-133	Case series	IV	Breastfeeding, swaddling, dim lights, minimal noise, avoiding unnecessary handling.
Legatte (2008)	Improving Pregnancy Outcomes: Mothers and Substance Abuse	<i>British Journal of Midwifery</i> , 16(3), 160-165	Retrospective chart review	III	Breastfeeding.
Marcellus (2007)	Neonatal Abstinence Syndrome: Reconstructing the Evidence	<i>Neonatal Network</i> , 26(1), 33-40	Case series	IV	Holding, swaddling, minimal stimulation, pharmacologic treatment.
Oei & Lui (2007)	Management of the Newborn Infant Affected by Maternal Opiates and Other Drugs of Dependency	<i>Journal of Paediatrics and Child Health</i> , 43, 9-18	Case series	IV	Breastfeeding.
Pitts (2010)	Perinatal Substance Abuse, Chapter 3	<i>Core Curriculum for Neonatal Intensive Care Nursing</i> (4th ed.)	Case series	IV	Music, swaddling, decreased noise, dim lights, rocking, pacifier, supine position.
Saiki, Lee, Hannam, & Greenough (2010)	Neonatal Abstinence Syndrome – Postnatal Ward versus Neonatal Unit Management	<i>European Journal of Pediatrics</i> , 169, 169-195	Retrospective cohort study	III	Rooming-in.
Velez & Jansson (2008)	The Opioid Dependent Mother and Newborn Dyad: Non-Pharmacologic Care	<i>Journal of Addiction Medicine</i> , 2(3), 113-120	Case series	IV	Pacifier, quiet environment, positioning in the supine position, slow vertical rocking, gentle pressure to posterior head.

continued on next page

**Table 2. (continued)
Systematic Review**

Author	Title	Document: Journal, Guideline, Chapter	Type of Study/Design	Level of Evidence	Intervention(s)
Wachman, Byun, & Philipp (2010)	Breastfeeding Rates Among Mothers of Infants With Neonatal Aspiration Syndrome	<i>Breastfeeding Medicine</i> , 5(4), 159-164	Retrospective chart review	III	Breastfeeding.
Wang (2014)	Perinatal Drug Abuse and Neonatal Drug Withdrawal	Medscape	Case series	IV	Swaddling, dim lighting, quiet environment, pacifier.
Western Australian Center for Evidence-Based Nursing & Midwifery (2007)	Management of the Infant with Neonatal Abstinence Syndrome (NAS) – Literature Review	Guidelines	Case series	IV	Quiet environment, swaddling, cuddling, massage, rocking, heart beat audiotapes, decreased stimulation, pacifier.
White-Traut et al. (2002)	Pulse Rate and Behavioral State Correlates after Auditory, Tactile, Visual, and Vestibular Intervention in Drug-Exposed Neonates	<i>Journal of Perinatology</i> , 22, 291-299	Randomized control trial	I-II	Auditory, tactile (massage) eye-to eye contact, vertical rocking.

**Table 3.
Levels of Evidence**

Levels	Types of Evidence
I-II	High-level evidence: randomized control trials
III	Retrospective cohort studies
IV	Case series

tion (Levels I and II) (Jansson et al., 2008; White-Traut et al., 2002). Interventions were gleaned from the evidence provided in the systematic review (see Table 3).

Systematic Review Results

Supportive Interventions

Infant comfort measures may be used to minimize the physiologic effects of withdrawal caused by the effects of central and autonomic system dysfunction (Greene & Goodman, 2003). Twenty journal articles, three Internet sites for guidelines, and one book chapter recommend supportive interventions for those neonates who do not require drug therapy or as an adjuvant to drug therapy. Supportive interventions include swaddling, gentle awakening, quiet environment with little stimulation, increased opportunities for non-nutritive sucking, and positioning. Eleven articles advocate

swaddling (American Academy of Pediatrics Committee on Drugs, 2012; Ballard, 2002; Beuman, 2005; Curet & Hsi, 2002; D'Apollito & Hepworth, 2001; Dodge, Brady, & Maguire, 2006; Greene & Goodman, 2003; Kuschel, 2007; Marcellus, 2007; Pitts, 2010; Velez & Jansson, 2008). Nine articles recommend a quiet environment with decreased stimulation and handling (Ballard, 2002; Beuman, 2005; D'Apollito & Hepworth, 2001; Dodge et al., 2006; Greene & Goodman, 2005; Kuschel, 2007; Pitts, 2010; Velez & Jansson, 2008; Wang, 2014). Non-nutritive sucking is supported by Beuman (2005), D'Apollito and Hepworth (2001), Greene and Goodman (2003), Wang (2014), and Velez and Jansson (2008). White-Traut et al. (2002), Greene and Goodman (2003), and Pitts (2010) choose vestibular stimulation (rocking) as a means of promoting physiological and behavioral functioning in drug-exposed infants. Positioning in supine position is recom-

mended in accordance with guidelines for avoiding sudden infant death syndrome (SIDS), unless the infant experiences stiffness (Beuman, 2005; Pitts, 2010; Velez & Jansson, 2008). Other recommended nursing practices are novel but not widely used. These innovative, supportive interventions include music therapy, massage, water beds, and the use of volunteers as cuddlers (Dodge et al., 2006; Fraser, Barnes, Biggs, & Kain, 2007; Greene & Goodman, 2003; Pitts, 2010). Rooming-in for neonates with NAS is a recent intervention. Several authors (Abrahams et al., 2007; Saiki, Lee, Hannam, & Greenough, 2010) compared rooming-in with traditional NICU care for infants with NAS. The authors found that newborns who roomed-in were less likely to require treatment for withdrawal and more likely to be discharged home with their mothers. They also found that rooming-in may promote more effective mothering and may reduce the prevalence and severity of neonatal withdrawal. Dodge and colleagues (2006), and Jambert-Gray, Lucas, and Hall (2009) also advocate rooming-in.

Nutrition

Neonates suffering from NAS may have impaired feeding behaviors, such as excessive sucking, poor feeding, regurgitation, and diarrhea,

which may result in difficulty with weight gain. For weight gain, supplementation with a high-calorie formula is recommended (Greene & Goodman, 2003; Wang, 2014). Small frequent feeds (gavage, if necessary) are recommended to aid in tolerating feedings and improving digestion (Ballard, 2002; Beuman, 2005; Pitts, 2010; Velez & Jansson, 2008). Should diarrhea or other gastro-intestinal disturbances occur, they are treated with the administration of an opioid compound (D'Apolilto & Hepworth, 2001; Greene & Goodman, 2003).

Skin Care

Neonates with NAS have a potential for skin breakdown as a consequence of diarrhea and diaper rash (Wang, 2014). Barrier ointments are recommended for avoidance of skin breakdown and diaper rash. If breakdown becomes severe, clear transparent dressings over reddened or excoriated areas may help avoid further problems (Beuman, 2005).

Breastfeeding

Several authors encourage breastfeeding for mothers who are chemically dependent on drugs, if not contraindicated (Ballard, 2002; Jansson et al., 2008; Jambert-Gray et al., 2009; Kuschel, 2007; Oei & Liu, 2007). Breastfeeding provides optimal nutrition, promotes bonding, and empowers babies' mothers to be effective parents (Jambert-Gray et al., 2009; Jansson et al., 2008; Leggatte, 2008). Unfortunately, only 24% of opioid-dependent mothers breastfeed, and 60% stop on the average after 5.9 days (Wachman, Byun, & Phillip, 2010). Breastfeeding also may decrease the severity of NAS, delay its onset, and decrease the need for pharmacologic treatment (Abdel-Latif et al., 2006)

National Guidelines

American Academy of Pediatrics. The American Academy of Pediatrics Committee on Drugs (2012) provides guidelines for the care of NAS. The committee advocates utilizing NAS scoring systems; drug therapy, if indicated; and supportive care interventions that include swaddling; high calorie formula, as needed; breastfeeding, if not contraindicated; frequent small feedings; and replacement fluids and electrolytes, if necessary. Observation of sleeping habits, temperature stability, weight gain or loss, or change in clinical status should

also be done to determine if there is a change in the neonate's condition or the potential for another disease process. Additionally, HIV, hepatitis B and C, and sexually transmitted infection (STI) screening is recommended.

Agency for Healthcare Research and Quality (AHRQ). The AHRQ has published guidelines for the drug-dependent woman on methadone who desires to breastfeed (AHRQ, 2010). Specific criteria are given to help the health care provider determine if breastfeeding the NAS patient is safe. To protect their privacy and provide confidentiality, women must give their consent to disclose their postpartum plans for addictions counseling and their progress in treatment with health care personnel. These women should also have a negative toxicology test at delivery. They must have received consistent prenatal care, have no contraindication to breastfeeding, and have counselor-endorsed achievement and maintenance of sobriety prior to and post-delivery. There are also criteria for those who should be discouraged from breastfeeding. For example, women who did not have prenatal care, who relapsed into substance abuse, or who refused substance abuse treatment should be discouraged from breastfeeding (Jansson et al., 2008). Jansson and colleagues (2008) conclude that research suggests that breastfeeding is not safe for neonates of chemically dependent mothers.

Western Australian Centre for Evidence-Based Nursing and Midwifery. The Western Australian Centre for Evidence-Based Nursing and Midwifery guidelines recommend that drug selection should match the type of agent causing withdrawal. The Centre also advocates NAS scoring systems; quiet environment; swaddling; gentle, firm handling; cuddling; massage; water therapy; and rocking. Playing heart beat audiotapes; small, frequent feedings on demand of hyper-caloric formula; and non-nutritive sucking are encouraged. Prevention of skin breakdown is accomplished with infants via mittens, sheepskin coverings for the crib or isolette, and frequent diaper changes.

Research and Current Practice

An informal survey of the procedures of a neonatal intensive care unit

and two published articles revealed results similar to the systematic review: Level IV interventions (supportive) are commonly used in the nursing care of NAS-affected neonates (Crossetti, Amin, & Jansson, 2007; O'Grady, Hopewell, & White, 2009). Swaddling, dim lights, quiet environment, and nutritional support are the majority of the interventions implemented. NAS scoring systems are becoming routine, with the Finnegan being the most used (O'Grady et al., 2009). The unit whose practices were reviewed has a protocol for obtaining meconium and urine samples from the neonate for drug testing upon admission to the NICU (S. Evankoe, personal communication, December 8, 2011). APN or MD orders are written for medication but not for supportive interventions. The timing of the interventions depends upon the NAS score and the onset of withdrawal symptoms. Breastfeeding, if not contraindicated, is encouraged by a majority of neonatal units (O'Grady et al., 2009).

Interventions recommended by the literature reviewed but not necessarily used by nurses are cuddlers, music therapy, massage, water beds, and rooming-in. Reasons for not providing these services could be cost, lack of personnel, hospital unit design, and reluctance to initiate new evidence-based protocols. Improvisation by nursing personnel could be an opportunity for improvement. Audiotaped soft music, and specific times with the mother and neonate in her hospital room (in addition to the times spent in the NICU visiting) are cost-efficient solutions. Nursing students could volunteer as cuddlers. Evidence is continually reviewed to obtain new information and confirmation of nursing practices already in place.

Nursing Interventions

The function of nursing interventions is to accomplish the objectives of nursing care. Therefore, the following interventions will allow best nursing practice according to the evidence from the literature:

- Do a thorough, accurate maternal history to determine if the neonate will be at risk. A drug history is included for all pregnant women, not just those who are suspected or confirmed substance abusers.

Table 4.
Scoring Systems for Neonatal Abstinence Syndrome

Scoring Tool	Range of Scores	Frequency of Scoring	Cutoff Score for Intervention
Finnegan Neonatal Abstinence Scoring System (NASS)	0 to 62	Hourly for the first 24 hours Every two hours for the second 24 hours Every four hours after 48 hours	Greater than 8
Lipsitz Neonatal Drug Withdrawal Scoring System (NDWSS)	0 to 20	Not specified	Greater than 4
Neonatal Withdrawal Inventory (NWI)	0 to 19	Not specified	Greater than 8
Neonatal Narcotic Withdrawal Index (NNWI)	0 to 14	Not specified	Greater than 5

Sources: Finnegan, Connaughton, Kron, & Emich, 1975; Green & Suffet, 1981; Lipsitz, 1975; Zahorodny et al., 1998. Zimmerman-Baer, Notzil, Renisch, & Ulrich Bucher, 2010.

- Screen all infants at risk with a reliable and valid NAS scoring instrument, which typically assesses symptoms of withdrawal and assigns a score in accordance with the severity of the symptoms (see Table 4).
- Provide supportive measures, such as swaddling, decreased stimulation, supine (or others as appropriate) positioning, massage, cuddling.
- Correct nutritional deficiencies with appropriate therapy (e.g., high-calorie formula, gavage feeds, IV therapy).
- Encourage the maternal-neonatal relationship through support for breastfeeding and rooming-in if there are no contraindications.
- Administer topical ointments or barrier shields for skin breakdown.
- Administer and monitor pharmacologic treatment if withdrawal is not contained by supportive measures. Gradually wean when appropriate.
- Collect samples for laboratory testing, if ordered.
- Assess and reassess NAS symptoms; if severe, act to prevent complications.
- Communicate and provide referral to social worker or other personnel for follow up post-discharge.
- Provide parenting education to caretakers of the neonate.
- Promote sleep by clustering interventions to avoid sleep disruption.

Objectives of Care

Nursing interventions are employed to meet the outcome objectives for the care of the neonate who has NAS. Objectives involve prevention or alleviation of withdrawal symptoms. The following are specific objectives for the nurse to achieve in providing comprehensive and quality care to the neonate with NAS:

- Provide safe, effective care.
- Avoid complications of body systems potentially affected by NAS.
- Maintain adequate nutrition.
- Promote maternal/parent infant bonding.

Evaluation of Interventions

Evaluation involves determining if the interventions based on the evidence obtained were successful. Data derived from the evaluation are used for determining if the goals of nursing care were met. There are several areas for evaluation. Symptomatology, nutritional status, and behavior are among data reviewed. Symptom relief is determined by assessment and reassessment of infant behavior and symptomatology. Results of laboratory tests also provide information on physiologic status. The use of a neonatal scoring system upon admission provides baseline data, which are then used to evaluate the progression of symptoms, the response to pharmacotherapy, and the resolution of symptoms (Fike, 2007). As the neonate recovers, the scores become lower. Meticulous observation and recording of intake and output, weight, and length are necessary, as

are appraisal of nutritional and fluid status (Hamden, 2010). Results of neurobehavioral tests should be part of the follow up (Wang, 2014).

Nurses who care for babies with NAS are motivated by the goal to provide excellent patient care. They also want to understand the rationale for the chosen nursing interventions. Toward that end, they seek evidence, not tradition, as the basis for best practices. Reading classic and translational literature, whether personally or by participating in committees to evaluate literature, determining interventions, and creating policy and procedure and/or nursing protocols for more efficient care of the neonate with NAS can help achieve that goal. ■

References

- Abdel-Latif, M.E., Pinner, J., Clews, S., Cooke, F., Lui, K., & Oei, J. (2006). Effects of breast milk on the severity and outcome of neonatal abstinence syndrome among infants of drug-dependent mothers. *Pediatrics*, *117*(6), e1163-1169.
- Abrahams, R.R., Kelly, S.A., Payne, S., Thiessen, P.N., Mackintosh, J., & Janssen, P.A. (2007). Rooming-in compared with standard care for newborns of mothers using methadone or heroin. *Canadian Family Physician*, *53*(10), 1722-1730.
- Agency for Healthcare Research and Quality (AHRQ). (2010). *Guidelines for breastfeeding and the drug-dependent woman*. Washington, DC: National Guideline Clearing House, U.S. Department of Health and Human Services. Retrieved from <http://www.guideline.gov/content.aspx?id=15262>
- Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project (HCUP) Nationwide Inpatient

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Goal

To provide an overview of neonatal abstinence syndrome and best practices as outlined in a literature review.

Objectives

1. Define neonatal abstinence syndrome.
2. Discuss the epidemiology of neonatal abstinence syndrome.
3. Explain supportive interventions based on this evidence-based practice literature review.

Statement of Disclosure: The author(s) reported no actual or potential conflict of interest in relation to this continuing nursing education activity.

The *Pediatric Nursing* Editorial Board members reported no actual or potential conflict of interest in relation to this continuing nursing education activity.

This independent study activity is provided by **Anthony J. Jannetti, Inc.** (AJJ).

Anthony J. Jannetti, Inc. is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

Anthony J. Jannetti, Inc. is a provider approved by the California Board of Registered Nursing, Provider Number, CEP 5387.

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This article was reviewed and formatted for contact hour credit by Rosemarie Marmion, MSN, RN-BC, NE-BC, Anthony J. Jannetti, Inc., Education Director; and Judy A. Rollins, PhD, RN, *Pediatric Nursing* Editor.

Sample. (2009). *HCUP facts and figures: Statistics on hospital-based care in the United States, 2009*. http://www.hcup-us.ahrq.gov/reports/factsandfigures/2009/TOC_2009.jsp

American Academy of Pediatrics (AAP) Committee on Drugs. (2012). Neonatal drug withdrawal. *Pediatrics*, *101*(6), e540-e560.

Ballard, J.L. (2002). Treatment of Neonatal Abstinence Syndrome with breast milk containing methadone. *Journal of Perinatal Neonatal Nursing*, *15*(4), 76-85.

Beuman, S.S. (2005). Identification and management of neonatal abstinence syndrome. *Journal of Infusion Nursing*, *28*(3), 159-167.

Cooper, C. (2004). *Frequently asked questions fact sheet series: Costs associated with the birth of drug and alcohol addicted/exposed infants*. Washington, DC: American University Bureau of Justice Assistance Drug Court Clearinghouse. Retrieved from <http://jpo.wrlc.org/bitstream/handle/11204/3258/1995.pdf?sequence=1>

Crocetti, M.T., Amin, D.D., & Jansson, L.M. (2007). Variability in the evaluation and management of opiate-exposed newborns in Maryland. *Clinical Pediatrics*, *46*(7), 632-635.

Curet, L.B., & Hsi, A.C. (2002). Drug abuse during pregnancy. *Clinical Obstetrics and Gynecology*, *45*(1), 73-88.

Davison, P., Worsley, A., & Husband, A.I. (2007). Drug withdrawal – The most common problems. *Hospital Pharmacist*, *14*(11), 363-365.

D'Apolito, K., & Hepworth, J.T. (2001). Prominence of withdrawal symptoms in poly-drug-exposed infants. *Journal of Perinatal and Neonatal Nursing*, *14*(4), 46-60.

Dodge, P., Brady, M., & Maguire, B. (2006). Initiation of a nurse-developed interdisciplinary plan of care for opiate addiction in pregnant women and their infants. *International Journal of Childbirth Education*, *21*(2), 21-24.

Fike, D.L. (2007). Substance-exposed infant. In C. Kenner, & J. Wright Lott (Eds.), *Comprehensive neonatal care* (4th ed., pp. 404-436). Philadelphia: W.B. Saunders.

Finnegan, L., Connaughton, J., Kron, R., & Emich, J. (1975). Neonatal abstinence syndrome: Assessment and management. *Addictive Disease*, *2*, 141-158.

Fraser, J., Barnes, M., Biggs, H., & Kain, V. (2007). Caring, chaos and the vulnerable family: Experiences in caring for newborns of drug-dependent parents. *International Journal of Nursing Studies*, *44*(8), 1363-1370.

Green, M., & Suffet, F. (1981). The Neonatal Narcotic Withdrawal Index: A device for the improvement care in the abstinence syndrome. *American Journal of Alcohol Abuse*, *8*(2), 203-213.

Greene, C.M., & Goodman, M.H. (2003). Neonatal abstinence syndrome: Strategies for care of the drug-exposed infant. *Neonatal Network*, *22*(4), 15-25.

Hamdan, A.H. (2010). *Neonatal abstinence syndrome*. Retrieved from <http://emedicine.medscape.com/article/978763-overview>

Huestis, M.A., & Choo, R.E. (2002). Drug abuse's smallest victims: In utero drug exposure. *Forensic Science International*, *128*, 20-30.

Jambert-Gray, R., Lucas, K., & Hall, V. (2009). Methadone-treated mothers: Pregnancy and breastfeeding. *British Journal of Midwifery*, *7*(10), 654-657.

Jansson, L.M. (2008). Neonatal abstinence syndrome, commentary. *Acta Paediatrica*, *97*(10), 1321-1323. doi:10.1111/j.1651-2227.2008.00968.x

Jansson, L.M., Choo, R., Velez, M.L., Harrow, C., Schroeder, J.R., Shakleya, D.M., & Huestis, M.A. (2008). Methadone maintenance and breastfeeding in the neonatal period. *Pediatrics*, *121*(1), 106-114. doi:10.1542/peds.2007-1182

Keegan, J., Parva, M., Finnegan, M., Gerson, A., & Belden, M. (2010). Addiction in pregnancy. *Journal of Addictive Diseases*, *29*(2), 175-191.

Kuschel, C. (2007). Managing drug withdrawal in the newborn infant. *Seminars in Fetal and Neonatal Medicine*, *12*(3), 127-133. doi:10.1016/j.siny.2007.01.004

Legatte, J. (2008). Improving pregnancy outcomes: Mothers and substance abuse. *British Journal of Midwifery*, *16*(3), 160-165.

Lipsitz, P.J. (1975). A proposed narcotic withdrawal score for use with newborn infants: A pragmatic evaluation of its efficacy. *Clinical Pediatrics*, *14*, 592-594.

Marcellus, L. (2007). Neonatal abstinence syndrome: Reconstructing the evidence. *Neonatal Network*, *26*(1), 33-40.

Oei, J., & Liu, K. (2007). Management of the newborn infant affected by maternal opiates and other drugs of dependency. *Journal of Pediatrics and Child Health*, *43*(1-2), 9-18. doi:10.1111/j.1440-1754.2007.00994x

O'Grady, M.J., Hopewell, J., & White, M.J. (2009). Management of neonatal abstinence syndrome: A national survey and review of practice. *Archives of Disease in Childhood (Fetal and Neonatal Edition)*, *94*, F249-F252. doi:10.1136/adc.2008.152769

Osborn, D.A., Jeffrey, H.E., & Cole, M.J. (2005). Sedatives for opiate withdrawal in newborn infants. *Cochrane Database of Systematic Reviews*, *3*, CD002053. doi:10.1002/1465/858.CD002053

Pitts, K. (2010). Perinatal substance abuse. In M.T. Verklan, & M. Walden (Eds.), *Core curriculum for neonatal intensive care nursing* (4th ed., pp. 41-71). Philadelphia: W.B. Saunders.

Saiki, T., Lee, S., Hannam, S., & Greenough, A. (2010). Neonatal abstinence syndrome – Postnatal ward versus neonatal unit management. *European Journal of Pediatrics*, *169*, 95-98. doi:10.1007/s00431-009-0994-0

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- Substance Abuse and Mental Health Services Administration (SAMHSA). (2012). *Results from the 2012 National Survey on Drug Use and Health: Summary of national findings* [NSDUH Series 4-46, HHS Publication No. (SMA) 3-4795]. Rockville, MD: Author.
- Sun, A-P. (2004). Principles for practice with substance abusing pregnant women: A framework based on the five social work intervention roles. *Social Work, 49*(3), 383-394.
- United Nations Office on Drugs and Crime (UNODC). (2013). *World drug report 2011*. Retrieved from <http://www.unodc.org/unodc/en/data-and-analysis/wdk-2313.html>
- Velez, M., & Jansson, L.M. (2008). The opioid dependent mother and newborn dyad: Non-pharmacologic care. *Journal of Addiction Medicine, 2*(3), 113-120. doi:10.1097/ADM.Ob013e31817e6105
- Wachman, E.M., Byun, J., & Phillip, B.L. (2010). Breastfeed rates among mothers of infants with neonatal abstinence syndrome. *Breastfeeding Medicine, 5*(4), 159-164. doi:10.1089/bfm.2009.0079.7e6105
- Wang, M. (2014). *Perinatal drug abuse and neonatal drug withdrawal* [last updated 2014]. Retrieved from <http://emedicine.medscape.com/article/978492-overview>
- Western Australian Centre for Evidence-Based Nursing & Midwifery. (2007). *Management of the Infant with Neonatal Abstinence Syndrome (NAS) – Literature review*. Retrieved from http://speciosum.curtin.edu.au/local/docs/nas/NAS_LitReview.pdf
- White-Traut, R., Studer, T., Meleedy-Rey, P., Murray, P., Labovsky, S., & Kahn, J. (2002). Pulse rate and behavioral scale correlates after auditory, tactile, visual, and vestibular intervention in drug-exposed neonates. *Journal of Perinatology, 22*(4), 291-299. doi:10.1038/sj/jp7210695
- Winklbaaur, B., Kopf, N., Ebner, E., Jung, E., Thau, K., & Fischer, G. (2008). Treating pregnant women dependent on opioids is not the same as treating pregnancy and opioid dependence: A knowledge synthesis for better treatment for women and neonates. *Addiction, 103*(9), 1429-1440. doi:10.1111/j.1360-0443.2008.02283.x
- Wright, R.W., Brand, R.A., Dunn, W., & Spindler, K.P. (2007). How to write a systematic review. *Clinical Orthopaedics and Related Research, 455*, 23-29.
- Zahorodny, W., Rom, C., Whitney, W., Giddens, S., Samuel, M., Maichuk, G., & Marshall, R. (1998). The Neonatal Withdrawal Inventory: A simplified score of newborn withdrawal. *Journal of Developmental and Behavioral Pediatrics, 19*(2), 89-93.
- Zimmerman-Baer, U., Notzil, U., Rentsch, K., & Ulrich Bucher, H.U. (2010). Finnegan Neonatal abstinence scoring system: Normal values for the first 3 days and Weeks 5-6 in non-addicted infants. *Addiction, 105*, 524-528.

Exploration of Internet Use: Profile And Preferences of Transition-Aged Adolescents with Spina Bifida

Cecily L. Betz, Kathryn A. Smith, Kristy Macias, and Kim Bui

Adolescents are enthusiastic Internet users, with estimates indicating that 93% of adolescents (12 to 17 years of age) and 89% of adolescents and young adults (18 to 24 years of age) access the Internet (Pew Internet and American Life Survey, 2009). Adolescents and young adults use the Internet primarily for social networking, while older age groups use the Internet for research, banking, and shopping purposes. Adolescents are also reported to use the Internet less frequently for health information (28%, 12 to 17 years) than older age groups (68%, 18 to 32 years) (Pew Internet and American Life Survey, 2009). Although findings from the Pew Survey may be associated with a variety of factors (such as developmental age, availability of computers with Internet access, and personal resources), it is timely that the potential use of the Internet for accessing health-related information by adolescents, specifically those with chronic illnesses who are transitioning to adulthood (including the transfer to adult health care), be explored – especially in a modernized culture where information is ever-growing and ever-reaching.

The purpose of this study was to explore Internet use among adolescents with spina bifida with regard to

Purpose: A pilot study was conducted to learn about the Internet usage of adolescents with spina bifida. The purpose of this study is to investigate the feasibility for developing an online health care transition intervention.

Methods: Use of the Internet was examined in a convenience sample of 50 adolescents with spina bifida in the Spina Bifida Clinic at Children's Hospital, Los Angeles. Participants were between 14 to 18 years of age. Data are reported as percentages and frequency distributions.

Results: Ninety-two percent of adolescents with spina bifida used the Internet, and of those, 87% used it at home, with an average rate of 2.4 hours per day. The majority of adolescents used the Internet for homework purposes (83%). Leisure activities, such as listening to music (76%), playing games (70%), meeting new friends/social networking (63%), and watching YouTube videos (61%), were also reported. Most participants have never used the Internet to obtain spina bifida information (67%) or to meet other adolescents with spina bifida (85%).

Conclusion: Internet application as an outreach tool for education and transition planning should be further explored in future studies. Given the widespread reported access to the Internet among our participants, results suggest that a Web-based outreach tool for education and health care transition planning have the potential to be accessible and beneficial to adolescents with spina bifida with the facilitated support of health care professionals.

its potential as a tool for patient education during the critical period of transition to adulthood, when making important future decisions regarding health care, education, employment, and lifestyle are dependent upon the knowledge of resources and skills in accessing them. To date, most studies have been conducted with adult samples; few studies have investigated Internet usage among adolescents with chronic illnesses. Recent studies have focused on several

chronic conditions, such as cancer, asthma, overweight/obesity, and HIV/AIDS (Bull, Pratte, Whitesell, Rietmeijer, & McFarlane, 2009; Doyle et al., 2008; Varni, Limbers, Burwinkle, Bryant, & Wilson 2008; Weisel, Weiss, Tasslimi, Alimokhtari, & Belby, 2008); however, no studies have been conducted with adolescents with spina bifida.

Review of Literature

Examinations of the use of online health interventions conducted with adults found several benefits that included reducing resource demands and cost, reducing health service costs, overcoming isolation, meeting the need for timely information, and reducing stigma associated with spinal cord disability (Goodman, Jette, Houlihan, & Williams, 2008). In a random survey of 2,038 participants, Kaye (2000) found that respondents with a disability or chronic illness were more likely to use the Internet to access health information and contact their physician through e-mail compared to

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respondents without disabilities. Disparities in Internet usage were found between individuals with disabilities as compared to those without disabilities; individuals with disabilities were less likely than individuals without disabilities to own a computer at home (23.9% versus 51.7%) and less likely to use the Internet (11.4% versus 31.1%). Kaye (2000) concluded that while the disability population is greatly skewed toward older ages, and older individuals are less likely to utilize modern technologies, these discrepancies are unaccounted for by differences in age.

The emerging literature on the application of the Internet for health-related purposes directed at children and adolescents has focused primarily on gaining an understanding of its feasibility for research and clinical purposes (Varni et al., 2008). Studies have been conducted with adolescents and young adults to evaluate its use for research data collection purposes (Varni et al., 2008), test the effectiveness of online health training programs (Doyle et al., 2008; O'Conner-Von, 2008), seek information related to chronic conditions (Schiffman, Csongradi, & Suzuki, 2008), and explore the trends in student use of a dedicated health information website (Santor, Poulin, LeBlanc, & Kusumakar, 2007). Other studies have investigated the use of the Internet to prompt or monitor health-related adherent behavior (Ruder, 2007; Weisel et al., 2008), initiate referrals to Internet-based prevention programs (Bull, Vallejos, Levin, & Ortiz, 2008; Walton et al., 2008), conduct online focus groups (Fox, Morris, & Rumsey, 2007), and offer online psychological treatment (Hicks, von Baeyer, & McGrath, 2006).

The use of the Internet for clinical application in adolescents with chronic illnesses was examined in several studies. In a sample of 80 overweight adolescents 12 to 17 years of age, Doyle et al. (2008) found that adolescents who received educational handouts on nutrition and physical activity reduced their body mass index (BMI) z-scores to a lesser degree than those who participated in a 16-week Internet-delivered program. Santor and colleagues (2007) explored the use of a health information website by 455 students in grades 7 through 12. The investigators found that students logged on more than 11,000 times during the year and that

students who wanted professional help, scored higher on depressive vulnerability measures, or reported severe mood problems logged on more frequently over longer periods of time than their counterparts. These results show that the mode of Internet delivery could be an effective health education tool compared to traditional methods and that a dedicated health information website for young people could offer significant opportunities for health promotion and early identification of difficulties.

Other studies examined the feasibility of using the Internet for clinically related supportive and research purposes. In a sample of 16 participants with cancer who were 13 to 29 years of age, Schiffman et al. (2008) found that adolescents and young adults with cancer reported being online for an average of 2.3 hours per day, preferring to visit cancer websites that provided the ability to chat with other adolescents and young adults with cancer as well as offer some type of game. Varni et al. (2008) found that the ePedsQL Internet method of administration had equivalent measurement properties to the well-established PedsQL paper-and-pencil method of administration among 92 children with type 1 and type 2 diabetes (ages 5 to 18 years) and their parents. As these studies reveal, research on the application of the Internet for clinical and research purposes for adolescents with chronic illness is in the seminal stages. Additional studies are needed to inform and provide evidence on its potential for health education and health care transition planning purposes.

A number of challenges are associated with the use of the Internet by adolescents in terms of obtaining health care information. A predominant issue is the lack of knowledge adolescents possess to critically evaluate the credibility of the website itself. In a sample of 10th and 11th grade students, while researchers found fluctuating reports of interest in evaluating science and health care career websites, they also found that role-playing reinforces students' ability to critically evaluate sites. Seventy-three percent of the students reported that they preferred the combination of workshop and role-playing activity; some said it increased their confidence in their ability to evaluate sites (Trettin, May, & McKeehan, 2008). According to a literature review by

Moreno, Ralston, and Grossman (2009) and subsequent expert opinion synthesis, adolescents' limited health literacy has been identified as a barrier to fully understanding the medical and health information available on websites. Fears of parental intrusion into their Internet use and legal issues pertaining to accessing health information before the age of majority were identified as well (Moreno et al., 2009).

These findings confirm the view that the Internet is indeed a useful tool in health education in the modern age, either in place of traditional methods or as a supplement to conventional models. However, barriers and psychosocial factors unique to adolescent life have only recently been recognized, and thus, understanding of Internet use by adolescents for health-related purposes and its potential for research and clinical purposes is in the seminal stages of development. Additional research is needed to better understand the future use of technologies, such as the Internet, to improve the quality of care provided to adolescents and their health outcomes, especially adolescents with chronic conditions. This is the first study to explore Internet use among adolescents with spina bifida.

Methods

Participants

A total of 54 participants were enrolled in our pilot study, with a final sample of 50 participants. The mean age of our sample was 16.1 years of age. We had a relatively even distribution between females (48%) and males (52%), and most of our participants were Latino/Hispanic (88%), while the remaining were Asian American (6%), African American (4%), and Caucasian (Non-Hispanic) (2%). Participants' grade levels ranged from 8th grade through college (see Table 1).

Four participants were excluded after their enrollment in the study. One participant did not have spina bifida, and another participant was excluded when history of mental illness was later revealed. In both instances, these adolescents verbally confirmed their eligibility upon enrollment. We later discovered facts to the contrary, necessitating their withdrawal from the study. In the case of the participant without spina bifida, the clinic physician treating the participant at the time revealed the

Table 1.
Demographics (N = 50)

Variable	Frequency (%)	n
Gender		
Male	52	26
Female	48	24
Age		
14	20	10
15	16	8
16	20	10
17	24	12
18	36	10
Ethnicity		
Latino/Hispanic	88	44
Asian/Pacific Islander	6	3
African-American	4	2
White (Non-Hispanic)	2	1
Grade level		
8th	8	4
9th	22	11
10th	18	9
11th	16	8
12th	30	15
College	6	3

patient's presence of a spinal cord injury in place of a spina bifida diagnosis over spontaneous conversation with a research assistant. The information regarding a history of mental illness for another participant was revealed through cross-referencing the enrollment database of a different study by the same principal investigator. We found that the same participant was excluded from enrollment in the past for having such history. The remaining two excluded participants had either an incomplete survey (missing data) or incomplete consent (missing signatures). Both participants were lost to follow up.

Tool

A 14-item questionnaire was created by study investigators who have extensive research and clinical experience with adolescents with spina bifida after conducting a review of literature related to Internet use by children and adolescents with chronic conditions. In this questionnaire, basic

demographic questions were asked in terms of age, gender, and ethnicity. We then asked for their grade level in school and assessed various aspects of Internet usage, including whether or not they use the Internet, where and how often they use the Internet, how much privacy they have while using it, types of activities engaged in while using it, and identification of their favorite websites. Adolescents were also asked whether they had ever used the Internet to obtain information about spina bifida or whether they had ever met other adolescents with spina bifida via Internet.

Procedure

We conducted this exploratory study with a convenience sample of 50 adolescents with spina bifida at the Spina Bifida Clinic at Children's Hospital, Los Angeles (CHLA). The 14-item questionnaire was administered to eligible adolescents who assented (with parental consent if under 18 years) or consented (if 18 years old)

during the patient's visit to the clinic. The inclusion criteria of the participants enrolled in the study were 1) 14 to 18 years of age, 2) diagnosis of spina bifida, 3) English-speaking, 4) no history of intellectual disability and/or a mental illness diagnosis, and 5) ability to complete the survey with or without assistance. Those who completed the questionnaire received an incentive of \$10 via a gift card. Data were inputted into Microsoft™ Access, and frequency/summary reports were generated from all closed and open-ended questions. The CHLA Committee on Clinical Investigations (CHLA's Institutional Review Board) approved the study.

Results

The majority of our participants reported use of the Internet (92%). When asked where they used the Internet, most reported using it at home (87%); other locations were reported as well (see Table 2). Youth indicated a myriad of types of Internet usage. The most frequently identified were school projects and homework (83%), listening to music (76%), playing games (70%), meeting friends (63%), watching YouTube videos (61%), and getting directions (43%). Participants reported using the Internet an average of 2.4 hours per day and 12.4 hours per week (see Table 2).

Most adolescents had privacy when using the computer (78%), while those without privacy claimed that the computer was located in the living room or some similar public place and/or that there was parental presence. The majority shared their computer with others (93%, citing various family members as the co-users) and did not have Internet access via their cell phone (80%), although several did use their cell phone to text message (68%) (see Table 3).

Two-thirds of adolescents had never used the Internet to look up information about spina bifida (67%). However, of those who did, most adolescents used Google (40%); other sources listed were Wikipedia and the Spina Bifida Association website (13% each), and the Children's Hospital Los Angeles website (7%). Most adolescents had never met other adolescents with spina bifida over the Internet (85%). Participants cited a number of favorite websites, including YouTube (30%), MySpace (24%), Facebook (11%), sports websites (11%), and Google (9%) (see Table 4).

Table 2.
General Internet Use Rates and Reasons

Questionnaire Items	Mean/Frequency <i>n</i> (%)
Do you use the Internet?	
Yes	46 (92)
No	4 (8)
Where do you use the Internet?	
Home	40 (87)
School	27 (59)
Someone else's home	13 (28)
Public library	13 (28)
Other public place	3 (7)
What do you use the Internet for?	
School projects/homework	38 (83)
Listen to music	35 (76)
Play games	32 (70)
Meet friends (social networking)	29 (63)
Watch YouTube videos	28 (61)
Get directions	20 (43)
Watch TV shows	17 (37)
Email	17 (37)
Watch or read about sports	17 (37)
Instant messages	14 (30)
News	13 (28)
Special interests	12 (26)
Shopping	5 (11)
Twitter	4 (9)

Discussion

Most adolescents in this study used the Internet at home and/or at school. This could be a direct reflection of the amount of time spent in school and time spent at home in general among adolescents, although it is unclear whether or not this may be exaggerated for those with chronic disabilities due to limited mobility. The majority of adolescents used the Internet for an average of over two hours per day, with over half of our sample using the Internet for school projects and homework, listening to music, playing games, meeting friends, and watching YouTube videos. Although our sample reported active use of the Internet, most adolescents had never used the Internet to look up information about spina bifida.

U.S. adolescents 12 to 17 years of age in the 2009 Pew Internet and American Life Survey reported a 93% rate of Internet usage, comparable to our 92% rate of Internet use among adolescents with spina bifida. High rates of playing games online, watching videos, and using social networking sites in the Pew Survey are also comparable to our sample (78%, 57%, and 65% in the Pew Internet and American Life Survey; 70%, 61%, and 63% in our sample, respectively). Twenty-eight percent of the adolescents in the Pew Survey reported getting health information online (Pew Internet and American Life Survey, 2009). Although our survey did not ask whether adolescents sought health information in general (but rather, if they specifically sought information about their spina bifida),

we similarly found a result of 33% reporting online searches regarding their condition. Thus, in terms of Internet use, the adolescents in our sample closely resemble adolescents described in other studies across the U.S. It is noted, however, that most of our sample of spina bifida adolescents are low-income (based on Medicaid eligibility); thus, our results are not generalizable to other adolescents in the U.S.

Our sample of adolescents with spina bifida reported Internet use with an average of 2.4 hours per day, comparable to the Schiffman et al. (2008) average of 2.3 hours per day among adolescents and young adults with cancer. Over half (56%) of Schiffman and colleagues' participants could not name a specific cancer website, while 87% of our participants could not name a spina bifida website. This may be due in part to a greater availability of cancer resources specifically geared toward adolescents as compared to spina bifida. An important factor in Schiffman and colleagues' (2008) findings is the popularity of games as a desired website feature, possibly reflecting the general popularity of video games among adolescents. Our sample of adolescents with spina bifida revealed that 70% used the Internet to play games online; therefore, this could be a determining factor in maximizing the potential and use of future web tools for adolescents with chronic illnesses.

As the findings reveal, most adolescents had not used the Internet to obtain information about their spina bifida or to network with peers with spina bifida. This finding was unexpected given the extent to which participants spent time on the Internet as well as their reasons for accessing the Internet. It is evident from their responses that these adolescents are familiar with the information retrieval and social networking properties of the Internet because the majority indicated using it to assist with their homework and for social purposes. A number of psychological factors may account for adolescents with spina bifida not using the Internet for informational and social purposes, such as developmental and family characteristics, as has been reported in studies of adolescents with chronic conditions wherein adherence to treatment regimens has been problematic (Betz, 2006; Betz, Smith, & Macias, 2010). Such factors may

Table 3.
Miscellaneous Items about Internet Use

Questionnaire Items	Frequency <i>n</i> (%)
Do you have privacy when you use the computer?	
Yes	36 (78)
No	10 (22)
If you don't have privacy, explain why:	
No response	4 (40)
Parents	3 (30)
Computer is in living room	2 (20)
School/library	1 (10)
Does anyone else use the computer besides you?	
Yes	43 (93)
No	3 (7)
If so, who else uses the computer?	
Siblings/Younger relatives	17 (40)
Parent(s)/Older relatives	9 (21)
No response	17 (39)
Have you met other teens with spina bifida on the Internet?	
Yes	7 (15)
No	39 (85)
Do you use your cell phone to go to the Internet?	
Yes	10 (20)
No	40 (80)
Do you use your cell phone to text message?	
Yes	34 (68)
No	16 (32)

include denial of diagnosis and the overall sensitive time period in which identity exploration and a desire to assimilate with peers is rampant (Hinds, 2001; Regber & Kelly, 2007). Although some adolescents may not feel the need to search for more information regarding the nature of their condition, additional investigations are warranted to better understand the reasons why adolescents with spina bifida do not use the Internet to seek out information and resources about spina bifida, particularly given the availability of information about spina bifida on the Internet.

Limitations

Despite what we have learned, the full range of Internet usage may not have been captured fully by the measures used in this study. Although we

have data on how often adolescents use the Internet, where, and what types of activities they engage in, we lacked open-ended questions to assess motivators for Internet use, positive and negative outcomes of usage, recommendations, and the like.

A second limitation of this study was the sample size. Due to the small numbers and convenience sampling, it is difficult to make generalizations. Because our sample was composed of mostly low-income, Hispanic adolescents receiving services in a specialty care clinic, our population may have different knowledge, health-related motivation, and socioeconomic status than other adolescents either with or without disabilities, impacting their access and usage of the Internet.

A third limitation was the use of self-report. It is possible that our

reported use rates and websites reflect a degree of social desirability bias with adolescents. It is also possible that information was underreported; many of the teenagers completed the survey with the surveillance/assistance of a parent and/or member of the research team. Further, an error in the design of the survey led to missing data for Internet usage rates per day and per week. For some participants, the item on our questionnaire regarding the usage of Internet in terms of hours per day and hours per week may have been ambiguous on our survey; it may have been unclear that estimates of time were required. This resulted in five non-responses for hours per day and seven non-responses for hours per week.

Finally, a fourth limitation in our study was the time constraint in completing the consent process and questionnaire during a single clinic appointment. Although the clinic setting was meant to be convenient and the survey was designed to be easily answered, we found that the limits of the clinic appointment involved competing demands for time with other members of the clinical team, as well as urgencies on the part of the participant to complete their appointment in a timely manner. This may have led to rushed, incomplete, or inaccurate answers.

Conclusion

The purpose of this study was to investigate the feasibility for developing an online health care transition intervention. The results suggest that a Web-based outreach tool for education and transition planning would likely be accessible and beneficial to adolescents with spina bifida with facilitated support from health care professionals. As predicted, the vast majority of teenagers with spina bifida in our sample used the Internet. With this knowledge, the application of a Web-based program as an outreach tool for education and transition planning could be potentially realized in the future. Because most of our teenagers reported using the Internet at home, transition planning online could have a broader reach than traditional in-clinic methods by increasing access and crossing physical barriers. Families can benefit from the savings associated with transportation costs and relief from the pressure to accommodate their children's participation in programs due

Table 4.
Specified Web Sites

Questionnaire Items	Frequency <i>n</i> (%)
Have you ever used the Internet to look up information about spina bifida?	
Yes	15 (33)
No	31 (67)
If yes, which website?	
Google	6 (40)
No response	5 (20)
Wikipedia	2 (13)
Spina Bifida Association	2 (13)
Children's Hospital Los Angeles	1 (7)
What website is your favorite?	
YouTube	14 (30)
Myspace	11 (24)
Facebook	5 (11)
No response	5 (11)
Sports websites	5 (11)
Google	4 (9)
Music websites	3 (7)
Television network websites	3 (7)
Clothing websites	2 (4)
Apple.com	1 (2)
Dictionary.com	1 (2)
Videogames sites	1 (2)

to inconvenient scheduling and the demand for allocation of family time. Adolescents can benefit from the increased pool of participants because they have been shown to value peer experiences, especially when they are health-related. The Internet could help to engage and provide a social forum for adolescents with spina bifida. Given that most adolescents are online, including adolescents with spina bifida, the Internet could be an ideal hub of resources for this unique population as well as for researchers who conduct studies with adolescents with chronic conditions.

References

Betz, C.L. (2006). Surgical preparation for children: The need for more evidence from nurse scientists. *Journal of Pediatric Nursing, 21*, 253-255.
 Betz, C.L., Smith, K.N., & Macias, K. (2010). Testing the transition preparation training program: A randomized controlled trial.

International Journal of Child and Adolescent Health, 3, 595-608.
 Bull, S., Pratte, K., Whitesell, N., Rietmeijer, C., & McFarlane, M. (2009). Effects of an Internet-based intervention for HIV prevention: The Youthnet trials. *AIDS & Behavior, 13*, 474-487.
 Bull, S.S., Vallejos, D., Levine, D., & Ortiz, C. (2008). Improving recruitment and retention for an online randomized controlled trial: Experience from the Youthnet study. *AIDS Care, 20*(8), 887-893.
 Doyle, A.C., Goldschmidt, A., Huang, C., Winzelberg, A.J., Taylor, C.B., & Wilfley, D.E. (2008). Reduction of overweight and eating disorder symptoms via the Internet in adolescents: A randomized controlled trial. *Journal of Adolescent Health, 43*, 172-179.
 Fox, F.E., Morris, M., & Rumsey, N. (2007). Doing synchronous online focus groups with young people: Methodological reflections. *Qualitative Health Research, 17*, 539-547.
 Goodman, N., Jette, A.M., Houlihan, B., & Williams, S. (2008). Computer and Internet use by persons after traumatic spinal cord injury. *Archives of Physical*

Medicine and Rehabilitation, 89(8), 1492-1498.
 Hicks, C.L., von Baeyer, C.L., & McGrath, P.J. (2006). Online psychological treatment for pediatric recurrent pain: A randomized evaluation. *Journal of Pediatric Psychology, 31*, 724-736.
 Hinds, P.S. (2004). The hopes and wishes of adolescents with cancer and the nursing care that helps. *Oncology Nursing Forum, 31*(5), 927-934.
 Kaye, S. (2000). Computer and Internet use among people with disabilities. *Disabilities Statistics Report 13*. Washington, DC: National Institute on Disability & Rehabilitation Research.
 Moreno, M.A., Ralston, J.D., & Grossman, D.C. (2009). Adolescent access to online health services: Perils and promise. *Journal of Adolescent Health, 44*, 244-251.
 O'Conner-Von, S. (2008). Preparation of adolescents for outpatient surgery: Using an Internet program. *AORN Journal, 87*, 374-398.
 Pew Internet and American Life Project. (2009). *Pew Internet project data memo*. Retrieved from http://www.pewinternet.org/~media/Files/Reports/2009/PIP_Generations_2009.pdf
 Regber, S., & Kelly, K.B. (2007). Missed opportunities – Adolescents with a chronic condition (insulin-dependent diabetes mellitus) describe their cigarette-smoking trajectories and consider health risks. *Acta Paediatrica, 96*(12), 1770-1776.
 Ruder, K. (2007). Text messaging for teens. *Diabetes Forecast, 60*, 28.
 Santor, D.A., Poulin, C., LeBlanc, J.C., & Kusumakar, V. (2007). Online health promotion, early identification of difficulties, and help seeking in young people. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(1), 50-59.
 Schiffman, J.D., Csongradi, E., & Suzuki, L.K. (2008). Internet use among adolescent and young adults (AYA) with cancer. *Pediatric Blood & Cancer, 51*, 410-415.
 Trettin, L.D., May, J.C., & McKeehan, N.C. (2008). Teaching teens to "Get Net Smart for Good Health": Comparing interventions for an Internet training program. *Journal of the Medical Library Association, 96*, 370-374.
 Varni, J.W., Limbers, C.A., Burwinkle, T.M., Bryant, W.P., & Wilson, D.P. (2008). The ePedsQL in type 1 and type 2 diabetes: Feasibility, reliability, and validity of the Pediatric Quality of Life Inventory Internet administration. *Diabetes Care, 31*, 672-677.
 Walton, M., Cunningham, R., Xue, Y., Trowbridge, M., Zimmerman, M., & Maio, R.F. (2008). Internet referrals for adolescent violence prevention: An innovative mechanism for inner-city emergency departments. *Journal of Adolescent Health, 43*, 309-312.
 Weisel, C.P., Weiss, S.H., Tasslimi, A., Alimokhtari, S., & Belby, K. (2008). Development of a Web-based questionnaire to collect exposure and symptom data in children and adolescents with asthma. *Annals of Allergy, Asthma, & Immunology, 100*, 112-119.

Experiences of School-Age Siblings Of Children with a Traumatic Injury: Changes, Constants, and Needs

Mary Jo Bugel

Accidental injury remains the number-one cause of disability for children over the age of one year in the United States (Centers for Disease Control & Prevention [CDC], 2003) and the number-one cause of nonfatal unintentional injury resulting in hospitalization for children 14 years of age and younger (CDC, 2011). Given that the average family with children under the age of 18 years in the United States currently has 1.92 children (United States Census Bureau, 2010), significant numbers of siblings in the United States have brothers or sisters with serious traumatic injuries. Existing research focusing on the experience of well siblings of children with traumatic injuries is sparse; further, there is no research about school-age siblings of traumatically injured children hospitalized for rehabilitative care. This unique age group of siblings is experiencing crisis at a personal level, as well as at a family systems level. Their lives are in turmoil, yet the experience of these children has not been studied as a distinct phenomenon.

This research study examines the lived experience of well school-age siblings of children who have sustained a serious traumatic injury from the perspective of the siblings. Major themes regarding changes and constants in the lives of the siblings are shared, along with the self-expressed needs of the siblings. Implications for nursing practice based on themes discovered in the data are presented and

School-age siblings experience a traumatic injury to their brothers or sisters in unique ways, yet little research has been undertaken regarding the sibling perspective. Understanding what it is like to be a well school-age sibling of a child with a traumatic injury is largely unknown. The aim of this study was to describe and understand the experience of being a well school-age sibling of a child recovering from a traumatic injury. Phenomenology was the method of inquiry used. Interviews were conducted with seven school-age siblings ranging in age from eight to 12 years, and were audio-recorded, transcribed, and analyzed using traditional qualitative techniques (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991). Identification of patterns and themes common to the experience were identified and described. Two major themes that emerged were the changes and constants that this experience brought to the siblings. The self-expressed needs of the siblings important to health professionals regarding communication and individual identity are shared. Research-based implications for the clinical practice of pediatric nursing are presented.

serve as guidelines for pediatric nurses working with families of traumatically injured children.

Review of the Literature

There is a gap in the literature regarding studies that have focused exclusively on the perspective of school-age siblings living through the experience during the traumatically injured child's recuperative phase. No studies exist regarding school-age well siblings of recently traumatically injured children who remain hospitalized for rehabilitative care. Other related studies exist but are focused on the perspective of the parents, adults, or adolescent siblings.

Gelmann (2000) described the sibling experience of previously healthy children hospitalized with a chronic illness or injury. Mainly interviewing adolescents, she identified seven themes: dispirited weariness, emotional turmoil, unrelenting anger, working through parental situation, sense of grief and loss, ways to cope, and uncertainty. Pit-Ten Cate and Loots (2000) explored experiences of 12- to 18-year-old siblings of children with physical disabilities, specifically about their coping skills and relation-

ships with peers, parents, and the child with disabilities. Findings showed that siblings had no problems with peer relationships associated with having a sibling with a disability, communication with their disabled brother or sister was difficult, and siblings desired changes in their parent relationships. Morrison (1997) studied self-reported stress in healthy school-age siblings of children who were hospitalized for acute illnesses and found that 77% of the siblings reported experiencing stress. Siblings who visited their brother or sister in the hospital more often were found to have more stress than those who visited less often, and sadness was found to be a common factor related to their stress. Swift et al. (2003) examined sibling relationships and outcomes for siblings of children with traumatic brain injury (TBI). Measures of sibling relationships were evaluated by the siblings, the injured children, and parents. The major finding was that at four years post-injury, mixed gender dyads of siblings of TBI children demonstrated more negative relationships than siblings in the non-TBI control group.

O'Hara et al. (1991) explored both siblings' and adult children's concerns related to living with a fam-

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Acknowledgment: This research was funded in part by the Gamma Nu Chapter of Sigma Theta Tau International Honor Society of Seton Hall University, South Orange, NJ.

ily member who was a TBI survivor. Participants, who were adults at the time of the panel discussion, were asked to remember back to experiences they had years ago as children or adolescents. Five themes were identified: more responsibility and less carefree time anymore, each day is a new experience, support and information on TBI is needed, parents need to support siblings, and community acceptance of TBI is needed. Gill and Wells (2000) conducted a retrospective study of the experience of living with a brother or sister with a TBI. Sibling participants were between 14 and 30 years of age. Only four participants were school-age children when the TBI occurred; of these four, two were teenagers and two were adults in their early 20s at the time of the interviews. Identified themes centered on personal changes in the sibling, being forever different, and self-discovery.

The findings in these studies are inconsistent regarding relationships and perceived stress levels of the siblings, and may not be generalizable to healthy siblings of traumatically injured children. By focusing on a different developmental age group, the previously unrevealed perspective of school-age siblings can be discovered. Studying this unique perspective is important because cognitive abilities and levels of understanding differ from age group to age group (Piaget, 1974; Piaget & Inhelder, 1969). Additionally, school-age children seem to be at particular risk for unrecognized threats to well-being when compared with older and younger children. Erikson's (1963) Eight Ages of Man holds that adolescents have a greater sense of independence than school-age children and are more readily able to seek out peer groups for support. Younger, pre-school children remain closely dependent on adults for the provision of basic needs, and when a family crisis occurs, it is more likely that they are left in the care of other caring adults. But school-age children who bridge the adolescent and pre-school age groups are frequently left on their own during a family crisis, yet they have little access to peers and after-school activities without adult facilitation.

Method

Phenomenology has been used by nurse researchers as a way of clarifying thoughts, connecting concepts

in new ways, discovering new knowledge to help in the understanding of the lived experience, and "describing human experience fully" (Lauterbach, 2007, p. 217). When knowledge about the lived experience is drawn directly from the perspective of the actual people involved in the phenomenon, a more appropriate, responsive, and need-fulfilling strategy of nursing interventions can be initiated. Because little is known about the experience of well school-age siblings of children with a traumatic injury, phenomenology was an appropriate methodology to answer the research question, "What is the experience of being a well school-age sibling of a child recovering from a traumatic injury?"

Van Manen's (1984, 1990) method of phenomenology was used in this research. The experience of school-age well siblings was explored, described from their perspective using their words, and analysis and interpretation were accomplished using data collected from siblings who were actually engaged in the phenomenon. A purposeful sample of seven well school-age siblings was recruited as research participants from a pediatric rehabilitation hospital in the Northeastern United States. The number of sibling participants was determined by the principle of data saturation commonly used in phenomenology (Polit & Beck, 2004); that is, data were collected until no new themes emerged.

Participants

Sibling participants were English-speaking, well, school-age children from eight through 12 years of age. All had a brother or sister who recently experienced a traumatic injury of some type in the past three months requiring in-patient hospitalization for a course of acute rehabilitation. The traumatic injury was defined as an acute, serious, damaging injury threatening the previously healthy child's physical well-being. The injured children required treatment to improve their post-injury functional abilities, which included multiple therapies and nursing care. The seriousness of the injury had an impact or impeded the affected child's growth and development in some way, and initiated a family crisis whereby family patterns of living were significantly disrupted, causing immediate and unexpected change in

the child's and family's lives.

When seeking out participants for a phenomenological study, researchers aim to find participants who have actually experienced the phenomenon under study. Generalizability of the findings is not a guiding principle. Although phenomenologists do not purposely seek diversity in the participant group, finding participants of diverse backgrounds who have experienced the phenomenon under study is desirable and occurred with this study's participant group. As shown in Table 1, siblings of all ages from eight through 12 years participated, as well as siblings of both genders. The index children (i.e., traumatically injured children) ranged in age from eight to 18 years, and also consisted of both males and females. Table 2 displays the age differences from sibling to index child, which ranged from seven years younger to three years older; the total number of siblings in the family, ranging from two to four; and the four categories of siblings' racial/ethnic groups. Three index children had the primary diagnosis of TBI, two had the diagnosis of multiple orthopedic injuries, and one child was diagnosed with a spinal cord injury. All injuries were the result of different types of accidental causes.

Data Collection

Data were collected through interviews with research participants conducted over a period of 13 months. The interviews were semi-structured, individual conversations with the school-age siblings and the researcher. The siblings spoke for themselves, using their own words, based on their own perspective and perceptions. Only the researcher and the sibling informants were present at the private interviews. All interviews were conducted in a conference room or office at the pediatric hospital. Each interview was audio-recorded on a small digital recorder, positioned inconspicuously in the room. Code numbers were assigned to each interview, and no real names were used. Interviews were transcribed verbatim. Privacy during the interviews was never breached, nor did any of the siblings have a serious or upsetting reaction during the interview. All siblings showed a favorable response to the interviews, and many displayed noticeable enthusiasm, as shown when one sibling spontaneously hugged the researcher and said, "Can we talk again!?"

Table 1.
Years of Age and Gender of Siblings and Index Children

Sibling Age (N = 7)	Number (Frequency)	Index Child Age (N = 6)	Number (Frequency)
8	1 (14%)	8	1 (17%)
9	1 (14%)	9	2 (33%)
10	1 (14%)	13	1 (17%)
11	3 (43%)	17	1 (17%)
12	1 (14%)	18	1 (17%)
Sibling Gender	Number (Frequency)	Index Child Gender	Number (Frequency)
Male	2 (29%)	Male	1 (17%)
Female	5 (71%)	Female	5 (83%)

Table 2.
Family Characteristics

Age Difference (years)	Number (Frequency)
-7 (Sibling younger)	1 (14%)
-6	1 (14%)
-4	1 (14%)
-2	1 (14%)
0 (Same age, twins)	1 (14%)
+2	1 (14%)
+3 (Sibling older)	1 (14%)
Total Number of Siblings in Family	Number (Frequency)
2	1 (14%)
3	5 (72%)
4	1 (14%)
Sibling's Racial/Ethnic Features	Number (Frequency)
Asian, Filipino	1 (14%)
Mixed*	1 (14%)
White, Hispanic	1 (14%)
White, Caucasian	4 (57%)

*Half African-American, half White-Portuguese.

Data Analysis

Phenomenology seeks to describe, identify, and understand basic psychological processes operating within the conscious experience of human beings as revealed by the actual people living the experience. It seeks to explore the experience of a phenomenon by allowing the essential meaning of the phenomenon to be discovered in the data and to be revealed as themes (Munhall, 1994, 2007; Van Manen, 1990). To accomplish these aims, data were analyzed in a way that themes were identified

and the meaning of the phenomenon was derived.

The written transcriptions of the interviews were read and re-read so that patterns and themes common to the experience of the school-age siblings became manifest. Much time was spent reflecting upon the data, which allowed for "dwelling" with the data (Munhall, 2007, p. 179) in such a way that a deeper understanding of the meaning of the experience was uncovered. Selective words and phrases in the transcriptions, that is, the spoken

words of the siblings, were labeled and coded using the traditional techniques described by Ely, Anzul, Friedman, Garner, and Steinmetz (1991). Categories were developed; labels, codes, and categories were linked and sorted as the primary level of extraction; patterns were identified; and themes were discovered as they revealed themselves. This process was not linear, but rather, it was cyclical. It involved continuously going back to the transcriptions and re-reading the words of the siblings as thematic identification and development was occurring. Ultimately, major themes and sub-themes were identified.

Findings

Changes

One theme discovered were the *changes* that school-age siblings experienced when their brothers or sisters became injured and entered into a rehabilitation hospital. Moreover, the changes that the siblings lived through were significant and considerable. Sub-themes included *change in the sibling relationship, involvement of other caring adults, sleep patterns, and daily routines*.

The most significant change acknowledged by siblings was the change in the sibling relationship. At some point in the overall experience, siblings realized that they did, in fact, love their brother or sister. Talking about her sister, one sibling said: "She loves me so much...she always wants to be with me. I always want to be with her." Another sibling explained the complicated relationship she had with her younger sister, which was previously typified by much fighting. During this experience, the sibling

claimed to become emotionally closer to her sister, explaining: "When I saw her, I was like, this isn't the girl I kept fighting with. It kind of drew me close to love her." Another sibling confirmed that he and his brother seem to have a better relationship now. He said that they usually fought "half-and-half" of the time they were together, but now "I think it's getting better because we talk a lot more." Previous conflicts and attitudes changed between the siblings and their brother and sisters, exemplified by one sibling's comment: "And now that the accident happened, everything is different. Everything's different. We have to take care of one another. And stop fighting with one another."

Another noteworthy change that was part of the overall experience for siblings was the increased involvement of other caring adults in their lives. Many times, it was the grandparents who provided the extra help needed during the crisis by providing care for the siblings, staying in the home, babysitting, and generally tending to the daily needs of the family and children. School-age siblings spent more time with their grandparents than usual, especially during the initial phases of the crisis. One sibling related: "My mom use to help me, but then my grandma came, and she helped me in the morning instead." Another sibling ended up staying at her grandparents' house for a month when her sister was injured. This sibling's other grandmother also traveled from a European country to the United States after the accident occurred to see the injured child and provide care for the school-age sibling. This sibling remarked that having her grandmother from another country live with her was something "different" for her. Another sibling stated: "We are never left alone 'cause I know some kids are." Her grandfather was always there to help the family.

Many things associated with sleeping and sleeping arrangements changed for the siblings. At times, this change was in the actual bed or bedroom, and involved a change from sharing a bedroom with another person, such as the injured child, to being alone in the room at night while sleeping. Sometimes this led to unsettled feelings about the new sleeping arrangements, which in turn led to the sibling sleeping in a room or bed with the parents. Sometimes siblings sought another comforting

place to sleep. Siblings exhibited these changes in sleep patterns and habits in different ways, but they spoke about this sub-theme freely. One sibling stated that the "biggest difference" in the entire experience for her was her new sleeping arrangement. She commented: "I don't sleep in my bed. I sleep in another room with my dad. Sometimes I sleep in his bed over the weekends, like when I fall asleep while watching a movie." She explained that she was accustomed to having her sister in the room with her, but since the accident and hospitalization of her sister, this sibling slept with her dad because she did not want to be alone in her own room "because I am not used to it." Another sibling related: "For me, the biggest difference is that my sister and I usually share a room...so that's kind of different for me [now] because me and my sister shared a room...I want to sleep with her." Another sibling, unable to sleep in the same room with her sister during the hospitalization, explained: "It's kind of lonely up there. I'm back sleeping in her bed. I sleep in her bed." Sleeping in her sister's bed seemed to be comforting to this sibling.

Aside from changes in sleep patterns, there were other changes in daily routines that siblings typically experienced in their daily lives. One sibling recounted that the most difficult thing about the entire experience was "not being home every day for dinner and stuff." At times it was the early morning routines of the siblings that changed. One sibling explained: "My routine before school was different because my mom used to wake me up. My mom used to help me in the morning." Her mom was not there in the mornings anymore, and other family members helped out. When it was her older brothers who helped her, she revealed that:

I usually have to wake myself up with an alarm. So I get myself up, get myself some breakfast, wake up my brothers, and tell them I have to be ready for the bus soon, and that I need someone to walk me down to my bus stop. Because my mom usually walks me down to my bus stop.

Another sibling missed taking the bus to school with her sister. She explained: "We'd sit in the same seat." She explained that not having her sister there with her on the bus

was hard for her. She commented: "I am used to her being next to me."

Another change in daily routines that emerged for siblings was an increase in the household chores and tasks they assumed. One sibling shared: "When my mom and dad are working, I usually clean the house with my [other, younger] sister. I clean the bathroom and everything. She helps me. We have fun." Similarly, another sibling talked about the chores he took on. He said:

I am starting to have more to do – a lot more stuff around the house. Usually I set the table...since my mom goes to the hospital a lot, I have to set the table, clear the table, feed the dog, and more of the little stuff.

He explained how he liked the additional chores, which changed his usual routine. He said: "I used to spend my days kinda relaxing and seeing what my friends could do so I can, like, hang with them. But now, I kind of like helping out more."

Constants

Although many changes occurred for the siblings, there were three sub-themes that remained constant in their lives. These sub-themes were *sibling rivalry*, *school life*, and *having fun*.

Even with positive changes in the sibling relationships, siblings still continued to experience previously established sibling rivalry. These old emotions and feelings did not become extinguished in the light of the current crisis but appeared to be deeply rooted. One sibling expressed the difficulty she experienced in seeing her sister get attention and gifts. She said: "She got so many presents! She got so much clothes, and I don't. She got her presents, and I don't have any." Small resentments and jealousies were still laced into affectionate relationships.

The time spent at school essentially stayed the same with little change for the sibling. When asked about whether things at his school were any different, one sibling responded: "No. Not really. School is OK. It is not really any different. School is about the same." Similarly, another sibling explained that school was "back to normal." Still another sibling shared: "School is mostly the same...actually, there isn't much difference at all." None of the sibling

participants ever experienced any problems regarding school or school-related activities.

For some sibling participants, the experience of having a brother or sister with a recent traumatic injury was initially a fun experience for them. One sibling said: "At first it was kind of fun...staying with friends, especially after school." Another sibling stated: "So I know some good things happened...I got to sleep at my friend's house on a school day. Yeah, it was fun for me." At times, siblings made new friends at the hospital, as one sibling explained: "Sometimes I talked to some of the kids in the playroom. I'd get to play with some of them. It was fun." The element of fun was not limited to spending more time with old and new friends, but rather, fun extended to participating in new and enjoyable activities. Some siblings spent time at the hospital participating in fun activities. Sometimes they played games with their brothers or sister, did art projects together, and attended organized therapy sessions. One sibling spoke about visiting the Recreation Room and explained the fun she had there with her sister: "We do stuff here actually, like the Rec Room, and we go there a lot together. And we will play ping pong together in that one room, and so we have fun." Sometimes siblings went to activities by themselves as well. Generally, siblings felt welcome in the Recreation Room.

Siblings Speaking Out

Siblings were asked if there was anything that they wanted adults to know. They were able to identify and express their own needs related to the experience and suggest ideas regarding how the needs of siblings could best be met by adults and health care professionals.

Siblings spoke about the need for recognition and validation of their identity and a confirmation of their own importance, apart from their brother or sister and the unfolding experience, and alluded to their frustration when they did not receive this validation. One sibling said: "I feel like I should be important, too, 'cause, usually my mom and dad give my sister everything she wants. I should be important, too." She continued: "I should be part of it, like important. That's how I feel. Uncomfortable. 'Cause me and my [other] sister are left behind."

Another sibling expressed a similar point of view. When asked what he would tell grown-ups about the experience if he were given the chance, he replied without hesitation: "That we're there, too. Don't forget us." Another sibling shared that he wanted adults to know: "It's just as hard for us as it is for them."

The lack of communication between siblings and nurses resulted in a lack of information for the siblings. Siblings talked about not being recognized and personally greeted by nurses on the clinical unit who were caring for their brother or sister, and how that related that to their need for information and communication. All siblings in the study felt ignored by the nurses at the hospital. One sibling stated that the nurses "usually [spoke to] my parents and my sister. Usually they just tell my parents, and I just eavesdropped." Listening-in and overhearing discussions was the method this sibling used to get new information about what was happening with her sister.

Informational needs were highlighted by another sibling as well. When this sibling first saw her injured sister, she wondered: "When is she going to be home? But, how did, how exactly did this happen?" This sibling wanted physicians and nurses to explain to her what happened. She explained: "They didn't really ignore us, but they need to give us more detail." She recommended: "Maybe they can tell the sisters or brothers what exactly happened. Tell us exactly what happened, what is exactly wrong, and where and how." Another sibling explained: "Some [nurses] would actually walk by me. Some would say 'hi.'" She believed: "Nurses and doctors, they only worry about the patient, and not the brothers or sisters." Another said that nurses "pretty much go right to my sister." It was this sibling's perception that the nurses did not do "anything" with her. Yet another sibling explained that nurses never said anything to him, not even "hi." If this sibling wanted or needed information, he sought information in a unique way, explaining that "sometimes, [the nurses] bring in this computer. Sometimes I stand behind and look at the computer because I know how to read that kind of stuff." Essentially, he looked over the shoulders of the nurses at the rolling computer-on-wheels to view information directly. He wanted to be

included in the information sharing and the decisions regarding care options for his brother. He said: "They [the nurses] should know how we feel, so they know how to treat everyone better."

Finally, another sibling spoke about seeing other hospitalized children at the hospital and his inability to understand or make sense out of what he observed. He related: "When I went to the hospital, I'd see all the other kids there. And I didn't know what they were there for. I didn't know what was going on." He said no one spoke to him about this, yet he wondered about what he saw and had questions.

Discussion

School-age siblings participating in this study shared their experience from the perspective of the here-and-now and how it affected them in their everyday lives. Findings were reflective of the concrete operations of thought and interpersonal relations that Piaget called the concrete operational stage of cognitive development (Piaget, 1951, 1974; Piaget & Inhelder, 1969). Piaget theorized that school-age children perceive and process the world around them in a more concrete way than older adolescents and comparatively have less capacity for abstract thinking. The siblings in this study responded to the more visual and empirical images before them in a concrete, age-appropriate way. They discussed realistic and practical ways that their lives were affected by the traumatic injury of their brothers or sisters rather than dwelling on a more abstract meaning of the experience.

School-age siblings expressed strong feelings of affection for their brother or sister, which were brought forth by the experience of the traumatic injury. This realization often led to siblings acting differently toward their brother or sister and a change in their feelings, which they described as becoming closer and the desire to spend more time with the injured brother or sister. Findings support that the sibling relationship can actually improve; siblings realized they did, in fact, love their brother or sister. The sibling relationship was never weakened; in fact, siblings reported that the experience fostered their relationship with their brother or sister and that they became closer through the experience. Talking about the

experience and her sister, one sibling said: "When I saw her...It kind of drew me close to love her." This statement is reflective of a more meaningful sibling relationship and deepened sense of maturity in this sibling. Gill and Wells (2000) reported a similar finding whereby siblings of children with a TBI reported feeling a "new closeness" (p. 51) toward their injured sibling.

The involvement of other caring adults in the lives of children, especially during times of family crisis, has been documented in the literature as *protective factors* (Luthar, Cicchetti, & Becker, 2000; Masten & Coatsworth, 1998). Luthar and colleagues (2000) emphasized the "importance of close relationships with supportive adults" (p. 545) as a mediating factor of stress that helps develop resilience in children. Similarly, Masten and Coatsworth (1998) identified attachment with caring adults as a protective factor for children in crisis. Ravindran and Rempel (2010) reported that involved grandparents of siblings of children with heart disease became advocates for the siblings and helped with physical and emotional care of the siblings. However, there is little evidence in the literature of the siblings' experience or response to grandparents being more closely involved in the family while a brother or sister is ill or injured. The siblings in this study enjoyed the increased contact with their grandparents.

Siblings in this study exhibited changes in sleep patterns and habits in different ways. Siblings experienced unsettled feelings about room or bed changes and/or the absent injured child, which in turn resulted in siblings sleeping in a room or bed with the parents. These alternate sleeping arrangements seemed to provide a more comforting place to sleep. A change in the sleeping patterns of siblings of ill or hospitalized children was not found in the literature, with one exception. Morrison (1997) reported that some of the stress experienced by siblings of hospitalized children manifested itself as "sleeping problems" (p. 27), but was not described further.

Erikson (1963) argued that the major developmental task for school age children is the development of a sense of industry versus a sense of inferiority. A sense of industry was fostered in the participants of this study by the changes in normal rou-

tines that were connected to the siblings' assumed additional household chores or tasks. These responsibilities, when successfully carried out, provided the opportunity for the school-age siblings to feel confident about themselves and become contributing members of the family unit. For example, one sibling commented on his new duties within the family routine: "But now, I kind of like helping out more." This suggests an increased sense of pride and accomplishment felt by the sibling related to his overall contribution to the family.

Siblings in this study experienced sibling rivalry and feelings of jealousy, which have been reported in other sibling studies (Akobeng, Miller, Suresh-Babu, Mir, & Thomas, 1999; Fleitas, 2000; Murray, 1998; Rozdilsky, 2005) with ill or disabled brothers and sisters. Because sibling rivalry is a normal and common occurrence in sibling relationships (Bank & Kahn, 1997; Bowlby, 2005), it seems legitimate that findings in this and other studies documented the conflicting responses of siblings, including jealousy and love, rivalry and caring. Sibling rivalry is one of the constituents that form the sibling bond, and even in the presence of the current family medical crisis, sibling rivalry remained a part of the normalization process.

The largely unchanged school life reported by the siblings was another stabilizing factor in their lives. Continued socialization with friends and classmates can be viewed as a protective factor, enhancing their sense of stability and normalcy, and in so doing, appears to serve as a mediator of stress. In her study on childhood burns, Lehna (2010) categorized school-related activities as "areas of normalization" (p. 248) for siblings. Additionally, the ability to continue having fun throughout the experience added to the stabilizing factors for siblings.

The self-expressed need for recognition and validation of the siblings' identities was in part connected to the pattern of communication that siblings experienced with health care personnel. The school-age siblings' concern regarding their apparent lack of recognition from health care personnel is understandable because this developmental age group still looks to adults for validation of self and confirmation of their importance. Fleitas (2000) reported that siblings became

resentful and lonely because they were ignored by physicians and nurses. The siblings' need to develop their own identity and be recognized was reported in Gelmann's (2000) study when a sibling asked, "Does anyone care about me?...I'm a person too" (p. 80). During this crisis when the energy of the entire family system is focused on stabilizing the health of the injured child, the school-age sibling is particularly vulnerable regarding the satisfaction of the need for identity. Bank and Kahn (1997) stated that it is: "Through the sibling relationship, one gets the sense of...being a distinct individual" (p. 15).

Siblings strongly declared their need for information, which was confirmed in studies of children with inflammatory bowel disease (Akobeng et al., 1999), siblings of critically ill children (Kleiber, Montgomery, & Craft-Rosenberg, 1995), siblings of acutely hospitalized children (Montgomery, 2000), and siblings of traumatically injured children (Johnson, 1995; O'Hara et al., 1991).

Strengths and Limitations

The glaring strength of this study was that it focused exclusively on the siblings' perspective. Data were collected from siblings who were actually immersed in the phenomenon at the time of the interviews, enhancing the fittingness of the data. Each sibling shared his or her experience willingly and honestly. Munhall (2007) stated, "Meaning is found in the transaction between an individual and a situation" (p. 162), so going directly to the siblings for their perspective and experience was, indeed, calculated and fitting, and provided the best possible findings from which to derive understanding of the human experience.

Data collection and data analysis were planned and carried out to enhance the trustworthiness of the study findings. Trustworthiness of the findings in qualitative research is evaluated by four criteria: *credibility*, *transferability*, *dependability*, and *confirmability*. Lincoln and Guba (1985) suggested techniques to increase trustworthiness of the findings, many of which were incorporated into the design and implementation of this study. Credibility and truth value of data were achieved through private and confidential engagement with the siblings, and supported by the development of trust between the

researcher and the individual siblings. Findings were extracted from the descriptive data drawn directly from the siblings' spoken words, thereby enhancing the fittingness of the findings; that is, "the findings of the study...fit' the data from which they are derived" (Sandelowski, 1986, p. 32). Criteria for the research participants were carefully developed and followed so that the siblings in the study were engaged in the experience regarding the phenomenon of interest. According to Lincoln and Guba (1985), the researcher does not transfer the findings; rather, the researcher provides the data for readers to make their own decisions regarding the potential transferability of the findings, as was done in this study.

Validity of findings is enhanced by member-checking, which "is the most crucial technique for establishing credibility..., provides the opportunity to assess intentionality..., [and] gives the respondent an immediate opportunity to correct errors of fact and challenge what are perceived to be wrong interpretation" (Lincoln & Guba, 1985, p. 314). During the actual conversations with the siblings, member checks were done regularly, mirroring back the researcher's understanding of the words the siblings were speaking.

Although different types of traumatic injuries were represented in the study, some typical traumatic injuries of children were not. For example, there were no diagnoses of burns or near-drowning, which would have been desirable to include. Siblings in this study were interviewed only one time, although the original research design planned for one to two interviews with each child. Practical and logistical considerations did not allow for more than one interview with each sibling; however, repetition of themes and data saturation were achieved.

Implications for Nursing Practice

The rich description of the experiences of these siblings and the themes that emerged provide a new knowledge base and deeper understanding of the experiences of well school-age siblings of children with traumatic injuries. Evidence-based recommendations for nursing practice regarding well school-age siblings rooted in the research findings and based on empirical data were developed. What are the specific implica-

tions that now exist for the practice of pediatric nursing?

Nurses need to discuss the experience of school-age siblings with parents regarding the research-based responses of siblings and alert parents to the needs of siblings. Early in the admission process, nurses can make the parents aware of research-based findings regarding school-age siblings' typical feelings, the need for recognition and validation, and the siblings' need for information.

Nurses must assess the needs of siblings as part of the overall family assessment, especially related to learning needs. Nurses should discuss with the parents the individual sibling's needs, what the sibling has have been told, how much he or she will be involved, how often the sibling will visit, what information is acceptable to share with the sibling, and what would be acceptable to the parent to teach the sibling regarding the injury to their hospitalized child.

All health care professionals, including nurses, need to greet siblings when they are present in the clinical area and address each sibling by his or her given name. Nurses should always learn the sibling's name and speak to the sibling in a friendly manner when he or she is visiting. At a minimum, nurses should say "hi" and ask the sibling how he or she is doing that day.

Whenever possible, siblings should be included in fun and recreational activities in which they can participate with their brothers or sisters. Nurses can help structure fun activities and/or initiate the sibling and the child going to recreation therapy together. Nurses may introduce the sibling to the recreation therapy staff and/or the child life staff.

With the parents' consent, the nurse can ask siblings if they have questions they would like answered, thus keeping siblings informed in an age-appropriate way. Nurses need to encourage and answer questions for the siblings in accordance with their developmental level and interest.

Siblings should be allowed opportunities to express themselves concerning their experience. When appropriate, the nurse can encourage siblings to speak candidly about their experience. Nurses should inform parents (and with parental permission, inform the sibling) about organized sibling support groups and activities that are available to them.

The nurse can speak with siblings regarding sibling rivalry and acknowledge that they may have feelings of jealousy. Although sibling rivalry is expected to continue, nurses can let siblings know that they understand siblings might be jealous of all of the attention their brothers or sisters are receiving, and it is normal for them to feel that way. Nurses are often the professional staff close by when siblings are reacting to sources of jealousy, such as presents and gifts being given to the hospitalized child.

Parents should know that increased involvement of grandparents and other caring adults has been experienced as helpful and comforting to school-age siblings. Nurses can discuss the positive benefits of allowing other adults to actively support siblings and help with family responsibilities at this time.

Finally, nurses should encourage parents to spend some alone time with siblings when possible, outside of the hospital experience. One aim of parenting is to lessen rivalry whether with well or ill children for better developmental outcomes. By spending alone time with the sibling, rivalry may be minimized.

Recommendations For Future Research

There is a need for follow-up longitudinal studies to examine the experience and reflections of these siblings as they move on to adolescence. How may life continue to change? Will the themes identified in the school-age years continue to be significant? Will there be a change in the quality of life for these siblings? Will the sibling relationship continue to become closer, or become strained and weaken? Additionally, it is recommended that future studies of siblings of children with traumatic injuries should include additional types of traumatic injuries that may be more visibly recognizable, such as amputations.

The findings in this study were concrete in nature and sibling-focused, and provide a deeper understanding of the meaning of this experience in the lives of well school-age siblings. The sibling participants in this study appeared to be coping competently with the experience of being well school-age siblings of children with a traumatic injury during the early rehabilitation phase of recovery. Nonetheless, it is essential

that the plan of care for these families include research-based strategies designed to meet the needs of siblings so nursing practice can truly be family-centered. ■■■

References

- Akobeng, A., Miller, V., Suresh-Babu, M., Mir, P., & Thomas, A. (1999). Quality of life of parents and siblings of children with inflammatory bowel disease. *Journal of Pediatric Gastroenterology & Nutrition*, 28(4), S40-S42.
- Bank, S., & Kahn, M. (1982/1997). *The sibling bond*. New York: Basic Books.
- Bowlby, J. (1979/2005). *The making and breaking of affectional bonds*. London: Routledge.
- Centers for Disease Control & Prevention. (2003). *Injury and violence prevention and control*. Retrieved from <http://www.cdc.gov/injury>
- Centers for Disease Control & Prevention. (2011). *Protect the ones you love: Child injuries are preventable*. Retrieved from <http://www.cdc.gov/safekid/NAP/background.html>
- Ely, M., Anzul, M., Friedman, T., Garner, D., & Steinmetz, A. (1991). *Doing qualitative research: Circles within circles*. London: RoutledgeFalmer.
- Erikson, E. (1963). *Childhood and society* (2nd ed.). New York, NY: Norton.
- Fleitas, J. (2000). When Jack fell down...Jill came tumbling after: Siblings in the web of illness and disability. *Maternal Child Nursing*, 25(5), 267-273.
- Gelmann, G. (2000). The experience of being a sibling of a hospitalized disabled child: A phenomenological perspective. *Dissertation Abstracts International*, 61(2), 1132.
- Gill, D., & Wells, D. (2000). Forever different: Experiences of living with a sibling who has a traumatic brain injury. *Rehabilitation Nursing*, 25(2), 48-52.
- Johnson, B. (1995). One family's experience with head injury: A phenomenological study. *The Journal of Neuroscience Nursing*, 27(2), 113-118.
- Kleiber, C., Montgomery, L., & Craft-Rosenberg, M. (1995). Information needs of siblings of critically ill children. *Children's Health Care*, 24(1), 47-60.
- Lauterbach, S. (2007). Meanings in mothers' experience with infant death: Three phenomenological inquires: In another world; Five years later; And what forever means. In P. Munhall (Ed.), *Nursing research: A qualitative perspective* (4th ed., pp. 211-238). Sudbury, MA: Jones & Bartlett.
- Lehna, C. (2010). Sibling experiences after a major childhood burn injury. *Pediatric Nursing*, 36(5), 245-251.
- Lincoln, Y., & Guba, E. (1985). Establishing trustworthiness. In *Naturalistic inquiry* (pp. 289-331). Newbury Park, CA: Sage Publications.
- Luthar, S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71(3), 543-562.
- Masten, A., & Coatsworth, J. (1998). The development of competence and unfavorable environments: Lessons from research on successful children. *American Psychologist*, 53(2), 205-220.
- Montgomery, L. (2000). *Needs of siblings of hospitalized children* (Doctoral dissertation). Retrieved from UMI's ProQuest Digital Dissertations. (Publication No. AAT 9996142).
- Morrison, L. (1997). Stress and siblings. *Paediatric Nursing*, 9(4), 26-27.
- Munhall, P. (1994). *Revisiting phenomenology: Nursing and health science research*. Sudbury, MA: Jones & Bartlett.
- Munhall, P. (2007). *Nursing research: A qualitative perspective* (4th ed.). Sudbury, MA: Jones & Bartlett.
- Murray, J. (1998). The lived experience of childhood cancer: One sibling's perspective. *Issues in Comprehensive Pediatric Nursing*, 21(4), 217-227.
- O'Hara, C., Ambrose, S., Costello, R., Davis, M., Goldfine, J., Hargrove, H., & O'Brien, D. (1991). Meeting the needs of siblings of traumatic brain injury survivors. *Cognitive Rehabilitation*, 9, 8-14.
- Piaget, J. (1951). *Play, dreams and imitation in childhood*. (C. Gattegno, & F. Hodgson, Trans.). New York: Norton.
- Piaget, J. (1974). *Understanding causality*. (D. Miles, & M. Miles, Trans.) New York: Norton.
- Piaget, J., & Inhelder, B. (1969). *The psychology of the child*. (H. Weaver, Trans.) New York: Basic.
- Pit-Ten Cate, I., & Loots, G. (2000). Experiences of siblings of children with physical disabilities: An empirical investigation. *Disability & Rehabilitation*, 22(9), 399-408.
- Polit, D., & Beck, C. (2004). *Nursing research: Principles and methods* (7th ed.). Philadelphia: Lippincott, Williams & Wilkins.
- Ravindran, V., & Rempel, G. (2010). Grandparents and siblings of children with congenital heart disease. *Journal of Advanced Nursing*, 67(1), 169-175.
- Rozdilsky, J. (2005). Enhancing sibling presence in pediatric ICU. *Critical Care Nursing Clinics of North America*, 17(4), 451-461.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.
- Swift, E., Taylor, G., Kaugers, A., Drotar, D., Yeates, K., Wade, S., & Stancin, T. (2003). Sibling relationships and behavior after pediatric traumatic brain injury. *Journal of Developmental & Behavioral Pediatrics*, 24(1), 24-31.
- United States Census Bureau. (2010). *Population survey: 2010 annual social and economic supplement*. Retrieved from <https://www.census.gov/hhes/www/poverty/publications/pubs-cps.html>
- Van Manen, M. (1984). *"Doing" phenomenological research and writing: An introduction* (Monograph no. 7). Alberta, Canada: University of Alberta.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario, Canada: The State University of New York.

Maternal Body Mass Index (BMI) Is Independently Associated with the Control of Diabetes Mellitus In Young Patients

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Improving glycemic control, as manifested by lowering levels of hemoglobin A1c (HbA1c), reduces the development of long-term complications of diabetes mellitus, such as retinopathy, nephropathy, and neuropathy (Diabetes Control and Complications Trial Research Group, 1993). Children with diabetes are especially vulnerable to develop these and other complications in early adulthood because of the duration of their disease (Donaghue, Chiarelli, Trotta, Allgrove, & Dahl-Jorgensen, 2009). Improving blood sugar management throughout childhood and adolescence, and therefore, preventing or postponing the development of morbid complications, has immense patient, family, and societal implications.

Prior research investigating family-level risk factors for poor glycemic control and the development of complications has been limited to genetic, clinical, and socioeconomic factors. For example, patients with diabetes who

Objective: Investigate the cross-sectional association of glycemic control of ethnically diverse youth with diabetes mellitus with family characteristics.

Design: Family study of 91 youth (probands) with diabetes mellitus and 142 parents.

Results: Children's age and HbA1c averaged 11.9 years and 8.9%, respectively; 69% were minorities. After adjustment, poor glycemic control was associated with minority race/ethnicity, more television viewing, and higher maternal body mass index (BMI). Average HbA1c was 1.2 and 1.9% units higher for children of overweight and obese mothers, respectively ($p = 0.004$).

Conclusions: The positive association between maternal body composition and child HbA1c likely represents the unique behavioral influence of mothers.

have siblings and/or parents with earlier onset of diabetic complications are more likely to have microvascular complications (Monti et al., 2007). Additionally, worse glycemic control and increased hospitalization rates are seen among patients from lower socioeconomic strata, minority groups, and underinsured families (Palta et al., 1997; Swift, Chen, Hershberger, & Holmes, 2006).

Microvascular complications of diabetes, such as nephropathy and

retinopathy, also aggregate within families, and several candidate genes have been identified (Abhary, Hewitt, Burdon, & Craig, 2009; Boright et al., 2005; Pezzolesi et al., 2009). Some evidence suggests increased genetic risk for coronary heart disease among persons with type 2 diabetes mellitus (Ruiz et al., 1994). Without question, genes play an essential role in developing complications; however, family environment also has an impact on an individual's ability to control glycemia, and thereby, prevent complications.

Research specifically on the health habits of family members, including parental body habitus, perceived stress, and exercise, eating, and television practices, has not been conducted with reference to families of children with diabetes. Adverse parental habits may place their children at greater risk of poor diabetes management. We addressed this question by investigating the association of glycemic control with these family characteristics in an ethnically and socioeconomically diverse group of families of youth with diabetes from the Chicago metropolitan area.

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Acknowledgments: This study was funded by the following grants: T32-DK064582-04S1; R01-DK44752; P60-DK20595; and UL1-RR024999. The authors would also like to acknowledge Deborah Burnet, Dianne Deplewski, Siri Atma Greeley, Latrisha Hampton, Diane Lauderdale, Elizabeth Littlejohn, Maureen Mencarini, Aida Pourbovali, Barry Rich, Lydia Rodriguez, Robert Rosenfield, Tracie Smith, Christine Yu, and especially the Chicago Childhood Diabetes Registry Family Study participants.

Methods

Study Sample

The Chicago Childhood Diabetes Registry Family Study traced the epidemiology and natural history of childhood diabetes in an ethnically diverse community sample. We recruited through diabetes clinics, health fairs, and mailings, and invited the index cases, children with any type of diabetes to participate if they were younger than 18 years of age at diagnosis and diabetes was not secondary to another condition. All biological first- and second-degree relatives were also invited to participate; however, non-parental/guardian participant data were not included in this analysis. We examined participants in their homes or in the General Clinical Research Center at the University of Chicago. Institutional Review Board approval was obtained. Parents provided informed consent, and children 10 to 17 years of age gave assent. This analysis focuses on the 91 patients who were younger than 18 years of age at the time of their participation, and includes information on their parents/guardians ($n = 142$) and family environment.

Data Collection

Data were collected via interviews, onset medical records, physical examinations, and biospecimens. Individual interviews collected information related to demographics, diabetes treatment and management, and health practices. In addition, the families selected one informant to provide family-level demographic and behavioral data.

Demographics. We defined patient race/ethnicity as that reported for three or more grandparents; if less than three grandparents shared the same race/ethnicity, the child was considered of mixed origin. When race/ethnicity was only available on one or two grandparents, parental data were used. HbA1c outcomes for non-Hispanic Black, Hispanic, and other/mixed families did not differ significantly, and the three groups were therefore combined and classified as minority race/ethnicity. Heads of household (defined as parent, main wage earner, or the person who makes the important decisions) reported health insurance status and total household income. Insurance was categorized into private insurance vs.

Medicaid/no insurance, and household income was dichotomized into below or at least \$50,000 per year. Mothers reported their highest level of education, which was dichotomized into school beyond high school vs. high school or less. Dichotomized income level was imputed for four missing responses using a prediction model based on food insecurity, number of parents in the home, maternal education level, and health insurance.

Diabetes characteristics. Parents who either reported having diabetes or had an elevated fasting glucose (≥ 126 mg/dL) measured by a glucometer (One Touch Sure Step, Lifescan, Milpitas, CA) were characterized as having diabetes in this analysis. Patients were definitively classified as having type 1 diabetes based on undetectable C-peptide, or detectable C-peptide with less than two years duration and positive islet autoantibodies (GAD, insulinoma-associated protein 2) ($n = 80$). The other patients were defined as having non-type 1 diabetes ($n = 11$; four of these did not use insulin). Fasting plasma C-peptide was measured in all patients. Those with a fasting blood glucose less than 150 mg/dL also had a stimulated plasma C-peptide measurement 90 minutes after ingestion of a 6 ml/kg standard nutrient solution (Boost, Novartis Nutrition Corporation, Minneapolis, MN). C-peptide was determined with a solid-phase, competitive chemiluminescent enzyme immunoassay (Immulite 2000, Diagnostic Products Corporation, Germany) in the University of Chicago's Diabetes Research and Training Center Lab. The lower limit of detection was 0.17 nmol/L and the intra-assay coefficient of variation (CV) was 8%. Detected C-peptide in patients whose fasting glucose was 150 mg/dL or higher was considered stimulated. Absent C-peptide was defined as level below the detection limit. Antibodies to radio-labelled recombinant human GAD 65 (whole) and human insulinoma-associated protein 2 (349 AA cytoplasmic portion) were quantified by fluid-phase immunoprecipitation assay. Children (or their guardians) were asked questions regarding their treatment regimen (insulin, pills, both, or diet). We calculated age at diagnosis and duration with diabetes based on information from the onset medical record; if not available ($n = 6$), date of diagnosis was self-reported. HbA1c in whole

blood was measured with the DCA 2000+ Analyzer (Bayer Healthcare, Elkhart, IN) using a latex immunoagglutination inhibition method. The intra- and inter-assay coefficients of variation were less than 4.3%, and the detection range for HbA1c was 2.5 to 14.0% (27 to 153 mmol/mol).

Family environment. Single vs. two-parent household was determined for each family. Heads of household were asked the six-item version of the United States Department of Agriculture (USDA) Household Food Security Scale designed to measure a household's ability to access enough food to fully meet their basic needs (for example, "In the last 12 months, did you ever cut the size of your meals because there wasn't enough money for food?") (Blumberg, Bialostosky, Hamilton, & Briefel, 1999). Families were considered food insecure if they responded affirmatively to two or more items. All participants were asked how often they eat together with people in their household and how many hours per week they spend viewing television. Parents answered the four-item version of the Perceived Stress Scale, a validated measure of the degree to which situations in one's life are appraised as stressful (for example, "In the last month, how often have you felt unable to control important things in your life?") (Cohen, Kamarck, & Mermelstein, 1983). The possible range of scores was 0 to 16, where a higher value indicates higher stress levels. Additionally, parents assessed their family's support for exercise using a 13-item Support for Exercise Scale (Sallis, Grossman, Pinski, Patterson, & Nader, 1987). These questions asked respondents to rate, for example, how often during the past three months their family "exercised with [him/her]" or "gave [him/her] encouragement to stick with an exercise program." Higher values indicated greater support, with a possible range of total scores being 13 to 65. Parents also reported their exercise frequency, dichotomized for analysis as exercising at least one day per week vs. less.

Anthropometrics. At the time of the interview, using standardized methods (Lohman, Roche, & Martorell, 1988), height was measured without shoes using a stadiometer rod, and weight (all participants) and percent body fat (those older than nine years of age and not pregnant) were meas-

ured with a bio-electrical impedance analyzer scale (Tanita TBF-300A, Arlington Heights, IL). Sixty-three of the patients were older than nine years of age and able to have valid body fat measurements. Body mass index (BMI) of children was transformed into Z-scores using age- and gender-matched reference data from the Centers for Disease Control and Prevention (CDC) (2000) Growth Charts. Maternal and paternal BMI was categorized into normal (< 25 kg/m²), overweight (25 to 30 kg/m²), and obese (> 30 kg/m²). BMI was not calculated for two pregnant mothers and was missing for one additional mother.

Insulin resistance. Serum insulin was measured with a solid-phase, two-site chemiluminescent immunometric assay (Immulite 1000, Siemens Medical Solutions Diagnostics, Los Angeles, CA) by the University of Chicago's Diabetes Research and Training Center Laboratory. Using fasting insulin and glucose, insulin resistance was determined for all participating parents without type 1 diabetes ($n = 133$) using the Homeostasis Model Assessment version 2.0 (Matthews et al., 1985; Wallace, Levy, & Matthews, 2004), available online (Oxford Centre for Diabetes, 2007). This mathematical model is a widely used tool to estimate insulin sensitivity and beta-cell function. Insulin resistance was not calculated for two pregnant mothers.

Statistical Methods

Linear regression analyses were conducted to identify significant correlates of the dependent variable, child's HbA1c. The association of each covariate with child HbA1c was evaluated individually; then covariates with p -values less than 0.15 were entered into multivariable analysis. Separate multivariable models were fit for each covariate category: patient characteristics, family characteristics, and maternal characteristics. Covariates significant in these models were combined into an overall multivariable model, and then non-significant covariates were dropped using a backwards selection approach to obtain a parsimonious model (Chatterjee & Hadi, 2002). Covariates not included in the parsimonious model were checked individually to determine whether they confounded the association between patient HbA1c and any of the covariates in the model.

Confounding was considered present if any regression coefficient changed by 10% or more when the potential confounder was added back into the model. No confounders were identified. Patient age, patient BMI Z-score, and maternal diabetes were added to the parsimonious model to obtain the final multivariable model; these covariates were included due to their historical association with HbA1c in previous studies and to facilitate comparison with analyses in similar studies. This multi-step approach to building the multivariable regression model was taken due to limitations on the recommended number of covariates for the given sample size. All analyses were conducted using STATA version 10.0 for Macintosh (College Station, TX).

Four sensitivity analyses were conducted by excluding certain subgroups from the final multivariable model (data not shown). In the first, patients not using insulin ($n = 4$) were excluded; in the second, patients classified as having non-type 1 diabetes ($n = 11$) were excluded. Neither of these exclusions substantially changed the results; all children were therefore included in the final analysis. A third sensitivity analysis excluded the two guardians who were aunts, again with no substantial change in the results; they were considered mothers for the purpose of this analysis. Finally, due to the higher number of mothers providing body composition data ($n = 89$) as compared to fathers ($n = 51$), we included only those families with two participating parents. In this restricted subgroup, we found results similar to the original model.

Results

Participants in the current analysis (see Table 1) included 91 children with diabetes, 89 biological mothers, 51 biological fathers, and two biological aunts/guardians. Participants were racially and ethnically diverse, with 31% of the patients non-Hispanic White, 42% non-Hispanic Black, 17% Hispanic, and 10% other/mixed race. For the children, mean age at examination was 11.9 years, ranging from 2.6 to 17.9 years. The majority used insulin monotherapy to treat their diabetes; however, three used pills only, two a combination of insulin and pills, and one diet alone. Eighty (88%) were definitively classified as having type 1 diabetes.

Mean (standard deviation) HbA1c was 8.9 (2.3%) or 74(25) mmol/mol, and ranged from 4% to 14% or 20 to 130 mmol/mol; mean BMI Z-score was -0.8 (0.7). For the parents, 10 reported having diabetes; a further five parents had fasting glucose results within a diabetic range. Mean BMI for mothers and fathers was 30.0 and 29.3 kg/m², respectively. Forty-eight percent of the households had Medicaid or no health insurance, 40% were single-parent homes, and 20% were considered food insecure. The patients watched 20 hours of television per week, on average.

In univariate analysis (see Table 2), several demographic factors were significantly associated with poor glycemic control in the children: older age at examination, minority race, lower family income, and Medicaid/no insurance. In addition, the association between older age at diagnosis and higher HbA1c approached statistical significance ($p = 0.09$). Duration of diabetes was not significantly associated with HbA1c.

We also explored various characteristics of the family environment. Children from single-parent homes were significantly more likely to have worse glycemic control. Additionally, there was a significant positive association between hours of television watched by the children and HbA1c. Food insecurity and family eating habits were not associated with the glycemic control of patients. Maternal and paternal perceived stress, perceived family support for exercise, and parental exercise and television habits were also not significantly associated with the child's HbA1c (data not shown).

Patient, maternal, and paternal obesity measures were analyzed for relationships with the child's HbA1c. A child's glycemic control was not significantly associated with his or her BMI Z-score, his or her percent body fat, paternal body BMI, paternal body fat, or paternal insulin resistance. In contrast, worse patient glycemic control was associated with greater maternal BMI, maternal percent body fat, and maternal insulin resistance. On average, in unadjusted analysis, overweight and obese mothers had children with HbA1c values 1.7% and 2.5% units (18.6 and 27.3 mmol/mol) higher than children of normal weight mothers, respectively ($p \leq 0.001$).

The presence of a parent with

Table 1.
Descriptive Statistics of Patients and Their Parents

Characteristic	n	n (%)	Mean (Standard Deviation)	(Range)
Demographics				
Age (years)	91		11.9 (4.0)	(2.6 to 17.9)
Male gender	91	49 (54)		
Minority race	91	63 (69)		
Family income less than \$50,000/year	91	50 (55)		
Medicaid/no insurance	91	44 (48)		
Maternal education (high school or less)	91	26 (29)		
Child's diabetes characteristics				
Age at diagnosis (years)	91		7.7 (4.0)	(0.9 to 15.9)
Duration with diabetes (years)	91		4.3 (3.2)	(0.1 to 15.6)
HbA1c (%); mmol/mol	91		8.9 (2.3); 97.3 (25.1)	(4.0 to 14.0); (44 to 153)
Type 1 diabetes mellitus	91	80 (88)		
Family environment				
Single parent home	91	36 (40)		
Food insecure ^a	91	18 (20)		
Family eating habits (eats together everyday)	90	42 (47)		
Child's TV viewing (hours/week)	90		20.0 (17.6)	(2 to 105)
Maternal TV viewing (hours/week)	90		17.3 (15.6)	(0 to 119)
Paternal TV viewing (hours/week)	50		12.0 (7.5)	(1 to 39)
Maternal perceived stress ^b	91		6.0 (2.7)	(1 to 15)
Maternal family support for exercise ^c	76		32.2 (9.3)	(19 to 59)
Maternal exercise (at least one day/week)	90	64 (71)		
Paternal perceived stress ^b	50		4.3 (2.9)	(0 to 11)
Paternal family support for exercise ^c	43		31.5 (9.6)	(21 to 53)
Paternal exercise (at least one day/week)	50	33 (66)		
Child's body composition				
BMI Z-score	91		-0.8 (0.7)	(-2.0 to 1.2)
Body fat (%)	63		27.4 (10.0)	(5.2 to 45.9)
Maternal body composition				
BMI (kg/m ²)	88		30.0 (7.4)	(17.5 to 48.3)
Body fat (%)	87		39.5 (8.3)	(20 to 54.8)
HOMA-IR	87		1.4 (2.1)	(0.3 to 18.2)
Paternal body composition				
BMI (kg/m ²)	51		29.3 (5.6)	(15.8 to 43.6)
Body fat (%)	51		27.1 (7.6)	(8.4 to 43.2)
HOMA-IR	46		1.2 (0.9)	(0.3 to 5.5)
Parents with diabetes				
Mother with diabetes	89	10 (11)		
Father with diabetes	51	5 (10)		
Either parent with diabetes	91	15 (16)		

Notes: HbA1c = hemoglobin A1c; BMI = body mass index; HOMA-IR = Homeostatic Model Assessment- Insulin Resistance.

^a Household Food Security Scale, insecure if answered affirmatively to at least 2 of 6 questions.

^b 4-item version of Perceived Stress Scale, higher value = greater stress, range 0 to 16.

^c 13-item Support for Exercise Scale, higher value= greater support, range 13-65.

Table 2.
Univariate Associations of HbA1c (%) with Patient, Parent, and Family Characteristics

Characteristic	n	β -Coefficient % (mmol/mol)	(95% C.I.-%) (95% C.I.- mmol/mol)	Intercept ^a % (mmol/mol)	p-value
Demographics					
Age (years)	91	0.14 (1.53)	(0.02, 0.26) (0.22, 2.84)	8.9 (73.8)	0.018
Minority race vs. non-Hispanic White	91	1.63 (17.8)	(0.66, 2.6) (7.21, 28.4)	7.8 (61.7)	0.001
Family income less than \$50,000/year vs. more	91	1.62 (17.7)	(0.72, 2.51) (7.87, 27.4)	8.0 (63.8)	0.001
Medicaid/no insurance vs. private	91	1.11 (12.1)	(0.19, 2.03) (2.08, 22.2)	8.4 (68.3)	0.019
Age at diagnosis (years)	91	0.10 (1.1)	(-0.02, 0.22) (-0.22, 2.4)	8.9 (73.8)	0.09
Family environment					
Single parent home vs. two	91	1.30 (14.2)	(0.37, 2.23) (4.04, 24.4)	8.4 (68.3)	0.007
Child's TV viewing (hours/week)	90	0.04 (0.44)	(0.02, 0.07) (0.22, 0.77)	8.9 (73.8)	0.001
Food insecure	91	0.48 (5.24)	(-0.71, 1.66) (-7.76, 18.1)	8.8 (72.7)	0.43
Family eating habits (eats together every day)	90	-0.22 (2.40)	(-1.18, 0.74) (-12.90, 8.09)	9.0 (74.8)	0.65
Child's body composition					
BMI Z-score	91	0.31 (3.39)	(-0.36, 0.97) (-3.93, 10.6)	9.1 (76.0)	0.36
Body fat (%)	63	-0.02 (0.22)	(-0.08, 0.05) (-0.87, 0.55)	9.2 (77.0)	0.58
Maternal body composition					
BMI categories (kg/m ²)	88				< 0.001
	26	Reference		7.4 (53.4)	
Normal weight (< 25)		1.66 (18.1)	(0.50, 2.82) (5.46, 30.80)		
Overweight (25 to 30)	24	2.46 (26.9)	(1.42, 3.51) (15.50, 38.4)		0.005
Obese (> 30)	38	0.10 (1.1)	(0.04, 0.16) (0.44, 1.75)	8.9 (73.8)	< 0.001
Body fat (%)	87	0.34 (3.72)	(0.12, 0.57) (1.31, 6.23)	8.9 (73.8)	0.001

continued on next page

diabetes in the family showed a trend toward significant correlation with worse glycemic control of the child ($p = 0.08$); the magnitude of the association was larger for maternal diabetes than for paternal diabetes.

In multiple regression analysis (see Table 3), higher patient HbA1c was significantly and independently associated with minority race, more hours of television watched per week by the

child, and higher maternal BMI, after controlling for the child's age at examination and BMI Z-score, family income, insurance status, and maternal diabetes. On average, patient HbA1c was 1.2% units (13.1 mmol/mol units) higher among those of minority race ($p = 0.03$), 0.02% units (0.22 mmol/mol units) higher for each hour of TV watched per week ($p = 0.05$), and 1.2% and 1.9% units (13.1

and 20.8 mmol/mol-units) higher for children of overweight and obese mothers, respectively ($p = 0.004$). These independent variables explained 31% of the total variance in patient HbA1c. First order interactions of maternal BMI with child BMI Z-score, age at exam, and gender on HbA1c were tested and none were significant.

Family income attenuated the effect of race while insurance status

Table 2. (continued)
Univariate Associations of HbA1c (%) with Patient, Parent, and Family Characteristics

Characteristic	n	β -Coefficient % (mmol/mol)	(95% C.I.-%) (95% C.I.- mmol/mol)	Intercept ^a % (mmol/mol)	p-value
Paternal body composition					
BMI categories (kg/m ²)	51				
Normal weight (< 25)	9	Reference		7.8 (61.7)	
Overweight (25 to 30)	23	0.51 (5.57)	(-1.10, 2.12) (-12.00, 23.2)		0.53
Obese (> 30)	19	1.21 (13.2)	(-0.45, 2.87) (-4.92, 31.4)		0.15
Body fat (%)	51	0.01 (0.11)	(-0.07, 0.09) (-0.77, 0.98)	8.5 (69.4)	0.81
HOMA-IR	46	0.18 (1.97)	(-0.49, 0.85) (-5.36, 9.29)	8.5 (69.4)	0.59
Patients with Diabetes					
Mother with diabetes	89	1.33 (14.5)	(-0.17, 2.83) (-1.86, 30.9)	8.8	0.08
Father with diabetes	51	0.94 (10.3)	(-1.00, 2.88) (-10.9, 31.5)	8.4	0.33
Either parent with diabetes	91	1.14 (12.5)	(-0.12, 2.40) (-1.31, 26.2)	8.7	0.08

^a Centered at sample mean for continuous variables.

Table 3.
Variables Significantly Associated with HbA1c (%) in Multivariable Model^a (n = 88)

Characteristic	β -coefficient % (mmol/mol)	(95% C.I.-%) (95% C.I.- mmol/mol)	p-value	Intercept ^a % (mmol/mol)
Minority race vs. non-Hispanic White	1.19 (13.0)	(0.15, 2.23) (1.64, 24.40)	0.026	6.0 (42.1)
Child's TV viewing (hours/week)	0.02 (0.22)	(0.00001, 0.05) (0.0001, 0.55)	0.05	
Maternal BMI Categories (kg/m²)			0.004	
Normal weight (< 25)	Reference			
Overweight (25 to 30)	1.24 (13.6)	(0.13, 2.36) (1.42, 25.80)	0.03	
Obese (> 30)	1.92 (21.0)	(0.81, 3.02) (8.86, 33.00)	0.001	

Note: CI=confidence interval.

^a Adjusted for patient age, family income, insurance status, patient BMI Z-score, and maternal diabetes. Only variables with $p < 0.05$ shown. Adjusted $R^2 = 0.31$.

had the opposite confounding effect; however, when both variables were included in the model, these opposing effects cancelled, and no confounding occurred. Maternal body fat and maternal BMI are measuring the same construct of maternal adiposity. When maternal body fat replaced maternal BMI in the final models, there was not a significant change to

the strength of the associations of other variables with HbA1c. Therefore, maternal BMI was used in the final model due to ease of interpretation and clinical application.

Discussion

In this analysis of 91 families of children with diabetes, we examined a

number of social, economic, and behavioral factors within the family. Although prior research on children with diabetes includes the child and his or her accompanying parent, this study is unique because of its broader family focus and the participation of many minorities. We found several indicators of economic status to be highly correlated with elevated HbA1c,

including low income, minority race/ethnicity, Medicaid or no insurance, and single-parent homes. Food insecurity, which correlates with higher BMI in other studies (Casey et al., 2006), and families frequently eating together, were *not* associated with glycemic control in this analysis. Our study found a strong association of greater maternal body habitus with higher HbA1c of young patients with diabetes. This finding is independent of race/ethnicity, family income, insurance status, child's age, child's body habitus, hours watching television, and maternal diabetes. Of note, although the average BMI of parents in this sample is high, it is consistent with estimates of national averages for low-income and minority families (Wang & Beydoun, 2007). Additionally, though there were fewer participating fathers, the variability of paternal body composition data was similar to that of mothers; therefore, restricted variability cannot account for the lack of association with patient HbA1c.

To our knowledge, the relationship between a mother's body composition and her child's glycemic control has not been described in the existing literature. Many studies have examined the relationship of maternal weight to diabetes onset; however, these studies typically focus on pre-pregnancy weight and its relationship with offspring adiposity and/or diabetes incidence (Boney, Verma, Tucker, & Vohr, 2005). Additionally, maternal type 2 diabetes, for which obesity is a major risk factor, correlates with worse glycemic control (Gong, Kao, Brancati, Batts-Turner, & Gary, 2008) and diabetic nephropathy (Hadjadj et al., 2007) in their offspring. Our results are the first to suggest that maternal body composition may have a significant impact on the glycemic control of offspring with diabetes. Perhaps the association between a mother's weight and her child's glycemic control could be explained by evidence that maternal BMI is positively associated with insulin resistance in non-diabetic offspring (Kazumi, Kawaguchi, & Yoshino, 2005). The young patients with diabetes in the current study who had heavier mothers may be more insulin-resistant than their counterparts with leaner mothers, and therefore, have a more difficult time maintaining glycemic control. Unfortunately, there is not a simple way to measure insulin resistance in

Existing research on children with chronic diseases suggests several possible mechanisms for the impact of family relationships on disease management that have important implications for nursing.

individuals with type 1 diabetes. Additionally, our study suggests that the association of maternal BMI with a child's glycemic control is independent of family tendency toward diabetes; adjustment for either maternal diabetes status or maternal insulin resistance did not change the magnitude of the association.

The mechanism of this relationship must therefore be further investigated. It is generally acknowledged that there is a substantial genetic influence on body composition, yet in our data, paternal body habitus was not related to patient HbA1c despite equivalent genetic contribution and an adiposity distribution that was similar to that of the mothers. This relationship continued to hold when we looked only at those families with two participating parents. Therefore, the strength of the association between glycemic control and mothers' adiposity, independent of paternal variables, likely represents the unique behavioral and environmental influence of mothers on the glycemic control of their children with diabetes. In the clinical setting, this may warrant particular attention to families of children with diabetes with overweight mothers. Nurses might use maternal adiposity as one indication that specific nursing interventions to improve lifestyle choices should be explored. Mothers are often the primary caretakers, including management of insulin and dietary intake of their children. Additionally, their own exercise habits may be passively or actively modeled for their diabetic children.

Our analysis includes several related socioeconomic factors whose impacts cannot be fully dissociated statistically from each other or from minority race. For example, the robust association of minority race with HbA1c of the patient, even after adjusting for family income and insurance, could be attributed to the residual socioeconomic impact of race in this sample.

There are limitations to our study. Recruitment was non-random

and may represent a bias toward families that were interested in the study and proactive enough in their care to present to clinic, attend diabetes fairs, or respond to mailings. However, the poor glycemic control seen in our study population does not support a bias toward adherent families with well-controlled diabetes. Additionally, HbA1c is certainly a traditional indicator of the adequacy of diabetes management, but it represents only one aspect of this multifaceted construct, and in this study, was measured at just one time point. The data are cross-sectional, yet the impact of family traits on a young person's disease outcomes will clearly be greater over the course of many years. We did not have longitudinal information on mothers' body habitus, although based on the current literature, it might be hypothesized that long-term maternal obesity could be one crucial determinant of glycemia in diabetic offspring. Self-reported behaviors, as included here, typically contain substantial error due to under- or over-reporting and social desirability biases within the family-centered interview, which cannot easily be accounted for. Finally, the sample of 91 patients and their families is not large enough to allow full exploration of all of the potential associations or to exclude the possibility of type II error. Of particular concern in this regard is the relatively small number of fathers who participated.

Conclusion

Existing research on children with chronic diseases suggests several possible mechanisms for the impact of family relationships on disease management that have important implications for nursing. Family climate may have an impact on patients' physiology directly by diet and exercise habits. Mothers may influence their children by modeling concern and behavior toward improving their own health issues. Some data exist showing that children who perceive their mothers as

collaborators in their diabetes management have better adherence to clinicians' recommendations and improved metabolic control (Wiebe et al., 2005). Our findings suggest that adult health behaviors may have a significant impact on child health outcomes. Maternal BMI may represent a combination of behavioral factors, such as eating behaviors, exercise habits, self-regulation capacity, and health self-efficacy and attitude, which are modeled for their children. Poorer glycemic control of their children may be a manifestation of adverse aspects of the home environment. The significant and independent association of television viewing with glycemic control of the patient highlights the behavioral and attitudinal aspects of diabetes management. Children who spent more time in sedentary activities or who had mothers with poor self-regulation were more likely to demonstrate worse glycemic outcomes. Thus, clinicians should consider devoting particular attention to families where the parents appear to have their own weight issues. This analysis has found that glycemic control of children with diabetes is strongly associated with their mothers' body habitus. For nurses, this result emphasizes the need to take family practices into consideration with young patients with diabetes. The optimal holistic approach to treating these vulnerable children must include not only patient-focused but family-focused approaches to lifestyle changes. There is some evidence that family interventions are effective in improving glycemic control, particularly when the interventions target diabetes-related stress and family conflict (Fisher & Weihs, 2000). Future nursing research among children with chronic illnesses should consider family health care attitudes and behaviors. Altering the caretakers' health beliefs and lifestyles may have both direct and indirect influences on the health of their children with diabetes. ■

References

- Abhary, S., Hewitt, A.W., Burdon, K.P., & Craig, J.E. (2009). A systematic meta-analysis of genetic association studies for diabetic retinopathy. *Diabetes*, *58*(9), 2137-2147.
- Blumberg, S.J., Bialostosky, K., Hamilton, W.L., & Briefel, R.R. (1999). The effectiveness of a short form of the Household Food Security Scale. *American Journal of Public Health*, *89*(8), 1231-1234.
- Boney, C.M., Verma, A., Tucker, R., & Vohr, B.R. (2005). Metabolic syndrome in childhood: Association with birth weight, maternal obesity, and gestational diabetes mellitus. *Pediatrics*, *115*(3), e290-296.
- Boright, A.P., Paterson, A.D., Marea, L., Bull, S.B., Mowjoodi, A., Scherer, S.W., & Zinman, B. (2005). Genetic variation at the ACE gene is associated with persistent microalbuminuria and severe nephropathy in type 1 diabetes: The DCCT/EDIC Genetics Study. *Diabetes*, *54*(4), 1238-1244.
- Casey, P.H., Simpson, P.M., Gossett, J.M., Bogle, M.L., Champagne, C.M., Connell, C., ... Weber, J. (2006). The association of child and household food insecurity with childhood overweight status. *Pediatrics*, *118*(5), e1406-1413.
- Centers for Disease Control and Prevention (CDC). (2000). *2000 CDC growth charts: United States*. Retrieved from: <http://www.cdc.gov/growthcharts>
- Chatterjee, S., & Hadi, A.S. (2002). *Regression analysis by example* (4th ed.). East Orange, NJ: John Wiley & Sons, Inc.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, *24*(4), 385-396.
- Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine*, *329*(14), 977-986.
- Donaghue, K.C., Chiarelli, F., Trotta, D., Allgrove, J., & Dahl-Jorgensen, K. (2009). Microvascular and macrovascular complications associated with diabetes in children and adolescents. *Pediatric Diabetes*, *10*(Suppl. 12), 195-203.
- Fisher, L., & Weihs, K.L. (2000). Can addressing family relationships improve outcomes in chronic disease? Report of the National Working Group on Family-Based Interventions in Chronic Disease. *Journal of Family Practice*, *49*(6), 561-566.
- Gong, L., Kao, W.H., Brancati, F.L., Batts-Turner, M., & Gary, T.L. (2008). Association between parental history of type 2 diabetes and glycemic control in urban African Americans. *Diabetes Care*, *31*(9), 1773-1776.
- Hadjadj, S., Duengler, F., Torremocha, F., Faure-Gerard, G., Bridoux, F., Boissonnot, M., ... Marechaud, R. (2007). Maternal history of type 2 diabetes is associated with diabetic nephropathy in type 1 diabetic patients. *Diabetes & Metabolism*, *33*(1), 37-43. Retrieved from http://www.cdc.gov/nchs/about/major/nhanes/anthropometric_measures.htm
- Kazumi, T., Kawaguchi, A., & Yoshino, G. (2005). Associations of middle-aged mother's but not father's body mass index with 18-year-old son's waist circumference, birth weight, and serum hepatic enzyme levels. *Metabolism*, *54*(4), 466-470.
- Lohman, T.G., Roche, A.F., & Martorell, R. (1988). *Anthropometric standardization reference manual*. Champaign, IL: Human Kinetics Books.
- Matthews, D.R., Hosker, J.P., Rudenski, A.S., Naylor, B.A., Treacher, D.F., & Turner, R.C. (1985). Homeostasis model assessment: Insulin resistance and beta-cell function from fasting plasma glucose and insulin concentrations in man. *Diabetologia*, *28*(7), 412-419.
- Monti, M.C., Lonsdale, J.T., Montimolo, C., Montross, R., Schlag, E., & Greenberg, D.A. (2007). Familial risk factors for microvascular complications and differential male-female risk in a large cohort of American families with type 1 diabetes. *Journal of Clinical Endocrinology & Metabolism*, *92*(12), 4650-4655.
- Oxford Centre for Diabetes, Endocrinology and Metabolism. (2007). *HOMA Calculator*. Retrieved from <https://www.dtu.ox.ac.uk/homacalculator/index.php>
- Palta, M., LeCaire, T., Daniels, K., Shen, G., Allen, C., & D'Alessio, D. (1997). Risk factors for hospitalization in a cohort with type 1 diabetes. Wisconsin Diabetes Registry. *American Journal of Epidemiology*, *146*(8), 627-636.
- Pezzolesi, M.G., Poznik, G.D., Mychaleckyj, J.C., Paterson, A.D., Barati, M.T., Klein, J.B., & Krolewski, A.S. (2009). Genome-wide association scan for diabetic nephropathy susceptibility genes in type 1 diabetes. *Diabetes*, *58*(6), 1403-1410.
- Ruiz, J., Blanche, H., Cohen, N., Velho, G., Cambien, F., Cohen, D., ... Froguel, P. (1994). Insertion/deletion polymorphism of the angiotensin-converting enzyme gene is strongly associated with coronary heart disease in non-insulin-dependent diabetes mellitus. *Proceedings of the National Academy of Sciences of the United States of America*, *91*(9), 3662-3665.
- Sallis, J.F., Grossman, R.M., Pinski, R.B., Patterson, T.L., & Nader, P.R. (1987). The development of scales to measure social support for diet and exercise behaviors. *Preventive Medicine*, *16*(6), 825-836.
- Swift, E.E., Chen, R., Hersherberger, A., & Holmes, C.S. (2006). Demographic risk factors, mediators, and moderators in youths' diabetes metabolic control. *Annals of Behavioral Medicine*, *32*(1), 39-49.
- Wallace, T.M., Levy, J.C., & Matthews, D.R. (2004). Use and abuse of HOMA modeling. *Diabetes Care*, *27*(6), 1487-1495.
- Wang, Y., & Beydoun, M.A. (2007). The obesity epidemic in the United States - Gender, age, socioeconomic, racial/ethnic, and geographic characteristics: A systematic review and meta-regression analysis. *Epidemiologic Reviews*, *29*, 6-28.
- Wiebe, D.J., Berg, D.A., Korbel, C., Palmer, D.L., Beveridge, R.M., Upchurch, R., ... Donaldson, D.L. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology*, *30*(2), 167-178.



Primary Care Approaches

Patricia L. Jackson Allen, MS, RN, PNP, FAAN

Spirometry in Primary Care for Children With Asthma

Nancy Cantey Banasiak

Asthma is the most common chronic condition diagnosed in childhood and has a significant impact on quality of life. In the United States, seven million children (9.5%) are living with asthma (Centers for Disease Control and Prevention [CDC], 2011). Non-Hispanic Black children and poor families have even higher rates of asthma, 16% and 13%, respectively (CDC, 2011). Asthma may be variable over time, and yearly spirometry, or more often as needed, should be used to evaluate disease severity and management. Asthma control, medication administration technique, the written asthma action plan, treatment adherence, and concerns should be assessed based on spirometry results at health care visits.

Two goals of asthma therapy are to reduce both respiratory impairment and risk of complications associated with asthma. Reduced respiratory impairment can be determined by decreased episodes of coughing or shortness of breath, use of inhaled short-acting beta₂-agonist (SABA) for quick relief of symptoms less than two days a week, and maintaining near-normal pulmonary function and the individual's normal activity levels. Risk reduction is characterized by the prevention of recurrent exacerbations of asthma and minimizing the need for emergency department (ED) visits or hospitalizations, prevention of reduced lung growth in children with asthma, and provision of optimal pharmacotherapy with minimal or no adverse effects of therapy (National Asthma Education and Prevention Program [NAEPP], 2007). Follow-up assessments and continuous monitoring of symptoms and management strategies are important to maintain goals. Objective measures of pulmonary function can be obtained by using a peak flow meter, but spirometry testing is considered a more reliable and valid measurement of respiratory function and asthma severity.

Spirometry

Spirometry is the preferred method of assessing lung function due to the accuracy of the test and the ability of

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Spirometry is an essential part of diagnosing a child with asthma. The National Asthma Education and Prevention Program (NAEPP) and the Global Initiative for Asthma (GINA) expert panels recommend spirometry to be performed on children five years of age and older as an objective assessment of lung function, to diagnosis asthma, and for ongoing yearly management of asthma (GINA, 2012; NAEPP, 2007). According to the NAEPP expert panel, history and physical examination alone are not reliable to accurately diagnose asthma, exclude alternative diagnosis, or determine lung impairment (NAEPP, 2007). Dombkowski, Hassan, Wasilevich, and Clark (2010) found 52% of physicians who provide primary care to children used spirometry, but only 21% used spirometry according to the national guidelines, and only 35% of physicians surveyed were comfortable interpreting the test results. Zanconato, Meneghelli, Braga, Zacchello, and Baraldi (2005) found that 21% of spirometry readings were interpreted incorrectly, concluding that proper training and quality control were important to provide if spirometry in the primary care office setting is to be used. The purpose of this article is to review the appropriate use of spirometry in pediatric primary care.

the test to diagnose acute and chronic lung disease in children. It is indicated to evaluate signs and symptoms of respiratory obstruction versus respiratory restrictive disease (see Table 1), measure the severity of the disease, determine the effect of medication on the disease, assess lung function pre-operatively, monitor the disease over time, and rule out other causes of wheezing (Miller et al., 2005; Patra, 2012). Spirometry should be repeated yearly to assess the child's asthma severity and control (NAEPP, 2007). The goals of spirometry are to provide an objective measurement of lung function, assess the degree of obstruction, evaluate the response to therapy, and assist with the decision to step up or step down therapy (Patra, 2012).

Spirometry Testing

In the past, spirometry testing has been performed in pulmonary clinics, but more recently, spirometry has been

The **Primary Care Approaches** section focuses on physical and developmental assessment and other topics specific to children and their families. If you are interested in author guidelines and/or assistance, contact Patricia L. Jackson Allen at pat.jacksonallen@yale.edu

Table 1.
Listing of Obstructive and Restrictive Lung Diseases

Obstructive Lung Disease
Asthma
Bronchiectasis
Chronic obstructive pulmonary disease (COPD)
Chronic bronchitis
Cystic fibrosis
Emphysema
Subglottic or tracheal stenosis
Tracheomalacia
Vascular ring
Vocal cord dysfunction
Emphysema
Interstitial fibrosis
Restrictive Lung Disease
Interstitial lung disease
Neuromuscular disorders
Obesity
Sarcoidosis
Scoliosis

Source: Adapted from Jat, 2013; Patra, 2012.

used in primary care practices to diagnose and monitor children with asthma. Different types of spirometers are available to practitioners from hand-held devices, requiring interpretation of results, to computerized devices with printed interpretation of test results and ranging in cost from \$500 to \$2,000. Personnel performing spirometry need to be trained in the use and calibration of the equipment to ensure accuracy. The health care provider offering interpretations or using spirometry to manage asthma in children should also be properly trained.

Miller and colleagues (2005) reviewed both the American Thoracic Society's and European Respiratory Society's statements on standardization of spirometry. Using both statements, the authors developed guidelines to standardize spirometry and developed guidelines for equipment requirements, acceptable techniques for testing, quality of patients' maneuvers during testing, standard bronchodilator dose and delivery for the reversibility testing, and recommendation for reporting data in a standard format (Miller et al., 2005). Further standards were developed for spirometry in the primary care setting and training requirements for personnel and quality control (Levy et al., 2009).

Proper technique is needed to perform an accurate spirometry test (Dombkowski, Hassan, Wasilevich, & Clark, 2010). The American Thoracic Society indicates personnel administering spirometry need to be properly educated, demonstrate proper technique, and follow a sequence of steps (Levy et al., 2009). It has been suggested that clinicians should perform at least five spirometry tests per week to maintain their skills (Levy et al., 2009).

Additional training is needed on how to coach children before and during the procedure with a demonstration of the steps required for successful testing. Children should practice using the mouthpiece and the nose clip (recommended but not required) so they will be cooperative and able to follow the directions for testing. Testing requires the child to exhale forcefully and then take a rapid deep breath with his or her mouth forming a tight seal around the mouthpiece of the spirometer without breathing through their nose. Then the child is asked to exhale forcibly while maintaining the tight seal with his or her mouth around the mouthpiece for at least six seconds. Children will often need to practice this technique before actual testing can be accomplished. This procedure should be performed until three acceptable measures are obtained but no more than eight times. Acceptable measures include adequate start and completion of test with age-appropriate effort by the child, a tight seal around the mouthpiece, and three acceptable spirometry graphs with similar results (Miller et al., 2005). Coughing, a common symptom in children with asthma, will interfere with testing, so testing the child when symptoms are well controlled is advisable.

Suboptimal testing may occur if the individual being tested has chest or abdominal pain, oral pain, urinary incontinence, altered mental status, has been smoking or consumed alcohol within hours of the test, or consumed a large meal within two hours of the test (Miller et al., 2005). Contraindications for performing spirometry include recent surgery, persistent cough, younger than five years of age, altered mental capacity or inability to follow instructions, recent pneumothorax or myocardial infarction, or inability to adequately seal the mouthpiece (Jat, 2013; Levy et al., 2009).

Other considerations for spirometry include the laboratory setting and infection control (Miller et al., 2005). The laboratory setting should be child-friendly in appearance, at ambient temperature, and with minimal distractions so the child can focus on the testing. Prevention of the spread of infectious disease is extremely important, especially in children with chronic respiratory conditions. All equipment must be cleaned between patients and tubing exposed to respiratory secretions discarded. Providers and technicians must wash their hands frequently and assure the mouthpiece being used is clean.

Interpretation of Spirometry Results

Spirometry results are vital in assessing pulmonary function, developing a diagnosis, and for ongoing monitoring of disease. It is critical to take into account the child's age, height, weight, gender, race, and time and dose of the last medications received that affect pulmonary function when interpreting spirometry results (Miller et al., 2005; Patra, 2012). This information should all be recorded as part of the spirometry record so results can be compared over time for the child. Normal spirometry values are values at or above 80% to 85% of the predicted value for that measurement in a healthy child of similar age and characteristic (Levy et al., 2009; Patra, 2012). The most common spirometry measurements tested include forced vital capacity (FVC), forced expiratory volume in 1 second (FEV1), FEV1/FVC ratio before and after the child is administered a short-acting beta2-agonist (SABA), and forced mid-expiratory flow (FEF25-75) (Chang, 2011; NAEPP, 2007). The measurements are helpful in determining respiratory obstruction, respiratory restriction, sever-

Table 2.
Patterns of Obstructive versus Restrictive Disease

	Obstructive (Asthma, COPD, CF)	Restriction (Scoliosis, obesity, neuromuscular disorders)
FVC	Normal or ↓ severe	↓
FEV1	↓	Normal or ↓
FEV1 /FVC	↓	Normal
FEF 25% to 75%	↓	Normal, ↑ or ↓

Sources: Adapted from Jat, 2013; NAEPP, 2007; Patra, 2012.

ity of respiratory disease, and if the respiratory condition is reversible with an inhaled short-acting beta2-agonist (see Table 2) (NAEPP, 2007).

Forced Vital Capacity (FVC)

Forced vital capacity (FVC) is the total amount of air the child can exhale forcibly after maximal inhalation. The child is instructed to take a deep breath in, insert the mouthpiece in his or her mouth, make a tight seal around the mouth piece, and blow out as hard as possible. A nose clip is recommended so air is not expelled through the nose. The child should be encouraged and coached throughout the procedure to blow as hard as possible until a plateau of the volume-time graph is seen, usually around six seconds, and then followed by normal inhalation to complete the maneuver. A decrease in FVC could indicate restrictive disease or severe obstructive disease (Patra, 2012).

Forced Expiratory Volume in 1 Second (FEV1)

The forced expiratory volume is the amount of air expelled in the first second as part of the FVC maneuver after maximal inhalation. FEV1 is one of the most common

measurements to assess obstruction or restrictive patterns. In obstruction disorders, FEV1 is decreased in moderate-to-severe cases, and in restriction patterns, FEV1 is either normal with mild disease or decreased (Patra, 2012). A 12% to 15% increase in FEV1 after inhalation of a SABA suggests reversibility of obstruction and a diagnosis of asthma responsive to SABA therapy (Jat, 2013; NAEPP, 2007). If the FEV1 does not increase, further evaluation is needed to rule out asthma (Jat, 2013).

Forced Expiratory Ratio (FEV1/FVC)

The ratio between the FEV1 and FVC should be calculated. The normal ratio for a child up to 19 years of age should be 85% and decreases to 80% for individuals 20 to 39 years of age (NAEPP, 2007). A normal ratio indicates the individual can exhale 85% of the lung volume in the first one second of a force exhalation (NAEPP, 2007). A decrease in both FEV1 and FEV1/FVC ratio indicates airway obstruction as seen with asthma (NAEPP, 2007).

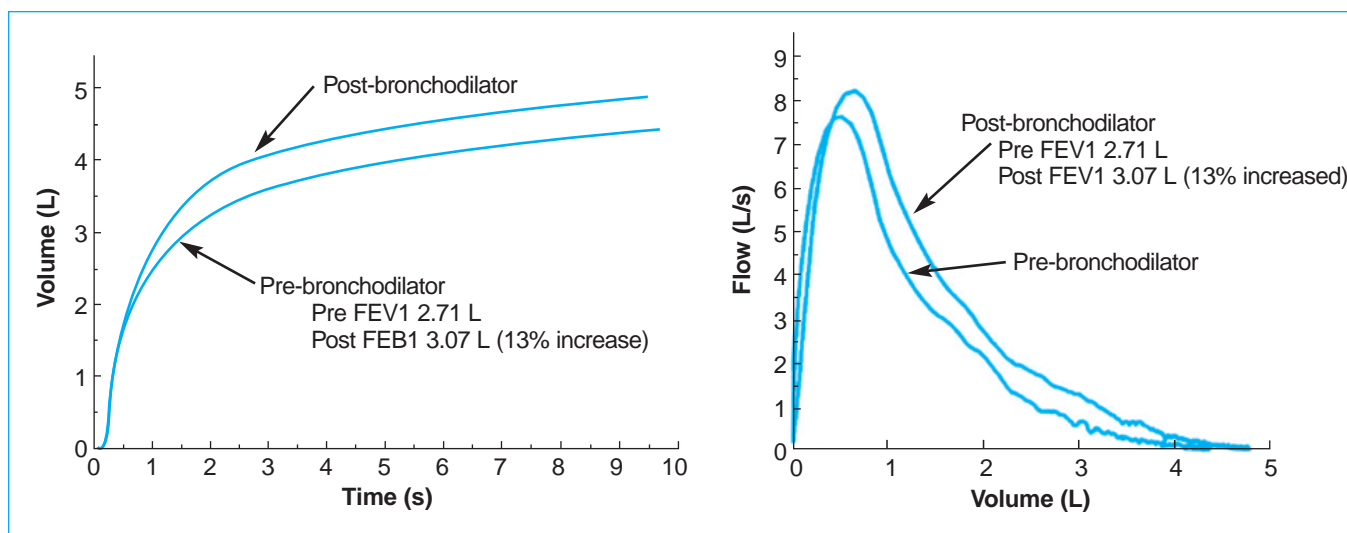
Forced Expiratory Flow (FEF 25% to 75%)

FEF 25% to 75% is the measurement of the forced vital capacity, excluding the first 25% and the last 25% of the expiratory phase (Patra, 2012). This is a measurement of small airway volume and may be decreased before any changes in the FEV1 or clinical symptoms are seen (Jat, 2013; Patra, 2012).

Spirogram

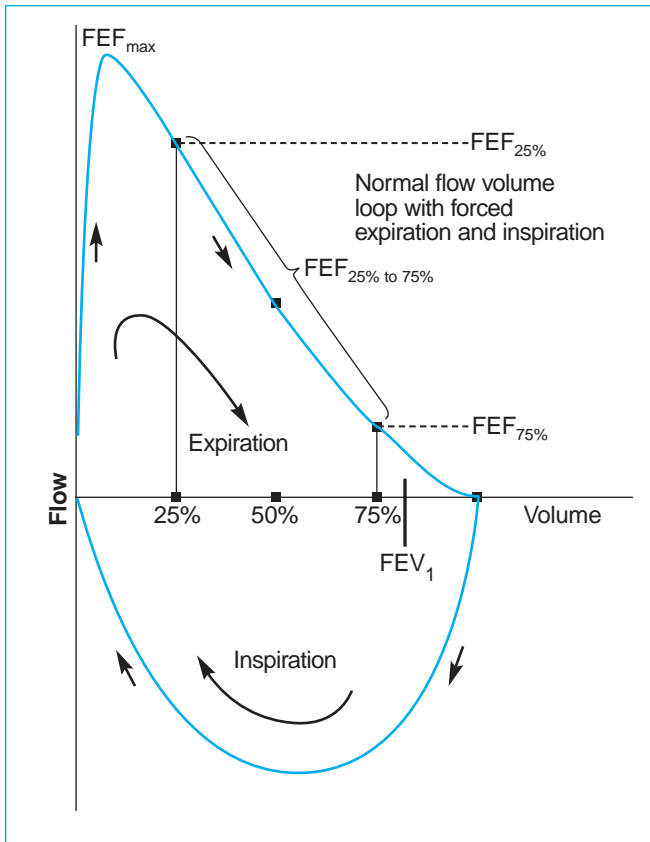
Data from spirometry testing are depicted in a graph form called a spirogram. The volume time curve, flow volume curve, and flow volume loop are important spirometry graphs for quality control (Jat, 2013). Respiratory disease or ineffective testing can be detected by the abnormal shapes of the curves in the spirogram (Jat, 2013). The volume time curve (see Figure 1) measures volume and time, with the X axis measuring time and the Y axis measuring volume. The volume time curve demonstrates the amount of exhaled air plotted against time required to exhale. The

Figure 1.
Spirograms: Volume Time and Flow Volume Curve



Source: NAEPP, 2007.

Figure 2.
Flow Volume Loop



Notes: FEV 1 = forced expiratory volume in 1 second, FEF 25% to 75% = forced expiratory flow, FVC = forced vital capacity.

Source: Sarnaik & Heidermann, 2011. Copyright 2011 Elsevier Saunders. Reprinted with permission.

flow volume curve (see Figure 1) measures flow versus volume. Both graphs demonstrate the difference in volume pre- and post-inhalation of bronchodilators. An increase of 12% or more from the pre-FEV1 to the post-FEV1 after bronchodilator medication use is indicative of obstruction with reversal, which is characteristic of individuals with asthma (Jat, 2013). A negative response to a bronchodilator challenge does not exclude asthma because of the variability of the disease (Jat, 2013). The flow volume loop (see Figure 2) measures inspiratory and expiratory flow against volume (on the X axis). The curve below the X axis represents inspiration, and the curve above the X axis represents expiration. The curve forms a loop that moves in a clockwise fashion. The highest peak on the graph is the peak expiratory flow rate (PEFR) or forced expiratory flow maximum (FEFmax), and the FEV1 is the amount of volume exhaled in one second as shown on the graph (see Figure 2). A decrease in FEV1 and FEV1/FVC ratio of less than 85%, and a decrease in FEF 25% to 75% are seen on the loop with obstructive disease like asthma.

Conclusion

Spirometry is an important diagnostic tool in establishing the diagnosis of asthma. Clinicians need to be comfort-

able with performing and interpreting readings after adequate training. Nurse practitioners caring for children with asthma need to conform to the National Heart, Lung and Blood Institute guidelines recommending spirometry as an objective assessment for the diagnosis of asthma. ■

References

Centers for Disease Control and Prevention (CDC). (2011). *Asthma in the U.S.: Growing every year*. Retrieved from <http://www.cdc.gov/vitalsigns/Asthma>

Chang, C. (2011). Asthma in children and adolescents: A comprehensive approach to diagnosis and management. *Clinical Reviews in Allergy & Immunology*, 43(1-2), 98-137.

Dombkowski, K.J., Hassan, F., Wasilevich, E.A., & Clark, S.J. (2010). Spirometry use among pediatric primary care physicians. *Pediatrics*, 126(4), 682-687.

Global Initiative for Asthma (GINA). (2012). *Global strategy for asthma management and prevention: Update 2012*. Retrieved from http://www.ginasthma.org/local/uploads/files/GINA_Report_March13.pdf

Jat, K.R. (2013). Spirometry in children. *Primary Care Respiratory Journal*, 22(2), 221-229.

Levy, M.L., Quanjer, P.H., Booker, R., Cooper, B.G., Holmes, S., & Small, I.R. (2009). Diagnostic spirometry in primary care. *Primary Care Respiratory Journal*, 18(3), 130-147.

Miller, M.R., Hankinson, J., Brusasco, V., Burgos, F., Casaburi, R., Coates, A., ... Wanger, J. (2005). Standardisation of spirometry. *European Respiratory Journal*, 26(2), 319-338.

National Asthma Education and Prevention Program (NAEPP). (2007). *Expert panel Report 3: Guidelines for the diagnosis and management of asthma* [Publication 08-405]. Bethesda, MD: National Institutes of Health. Retrieved from <http://www.nhlbi.nih.gov/guidelines/asthma/asthsumm.htm>

Patra, K.P. (2012). Focus on diagnosis: Spirometry. *Pediatrics in Review*, 33(10), 469-472.

Sarnaik, A., & Heidermann, S. (2011). Respiratory pathophysiology and regulation. In R.M. Kliegman, B.S. Stanton, J.W. St. Geme, N.F. Schot, & R.E. Behrman (Eds.), *Nelson textbook of pediatrics* (19th ed.) Philadelphia: Elsevier Saunders. Retrieved from <http://www.expertconsult.com>

Zanconato, S., Meneghelli, G., Braga, R., Zacchello, F., & Baraldi, E. (2005). Office spirometry in primary care pediatrics: A pilot study. *Pediatrics*, 116(6), e792-e797.

Additional Reading

Kliegman, R.M., Stanton, B.F., St. Geme, J.W., Schor, N.F., & Behrman, R.E. (2011). *Nelson textbook of pediatrics* (19th ed.). Philadelphia: Elsevier Saunders.



Critical Thinking Case Studies

Tedra S. Smith, DNP, CRNP, PNP-PC

Decreased Solid Food Intake in a Toddler: Is That a Problem?

Tedra S. Smith

Case Presentation

Anna is a 15-month-old, African-American female presenting to the primary care clinic as a walk-in with her mother. Her mother reports that Anna has had decreased solid food intake for quite some time and has now developed nasal drainage. Her mother expressed concern because Anna appears to be losing weight. She also reports that Anna has had a mild cough over the past few days and the general appearance of not feeling well. Anna does not have any health problems and no scheduled daily medications. Her mother reports that she has not given Anna any over-the-counter medications, including vitamins.

History of Present Illness

Anna's mother reports that the decreased food intake has been going on over the past three months. The cough, however, just started two days ago. Anna has a general dislike of certain foods but had been her usual self until the cough started. Her mother reports the cough is usually worse at night and that Anna has clear nasal drainage at times.

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Past Medical History

Anna has been seen at this clinic since birth. Her immunizations are up to date, and she has been seen a few times for cold symptoms. Anna has had the occasional cough and runny nose, but no other illnesses according to her mother. Her mother also denies any known drug or food allergies.

Development and Growth History

Anna's mother reports that she had an uncomplicated pregnancy and vaginal delivery. She received prenatal care and was 37 weeks pregnant at the time of the delivery. Anna has developed normally except that she seems to now be losing weight according to her mother. She was able to sit-up at age five months, crawled at age eight months, and began walking right before her first birthday. She takes the bottle once or twice a day, but primarily uses a cup.

Family and Social History

Anna's mother denies any family history of asthma, sickle cell disease, heart disease, or diabetes. Anna's paternal grandmother had breast cancer, but her mother denies any other paternal health problems or any significant maternal history. Anna lives with her mother and maternal grandmother. She currently does not attend daycare, and her mother denies that anyone smokes inside the home. Her mother works at a fast food restaurant. Anna's

father's place of employment is unknown.

Nutritional History

According to her mother, Anna is a very picky eater and only snacks throughout the day. She takes in about 24 to 48 oz. of whole milk each day, as well as an unknown amount of fruit juices. Her mother reports that she mainly feeds her table food, but Anna often refuses and drinks milk during mealtime. Her mother provided the following 24-hour diet recall:

- Breakfast: Cereal with whole milk.
- Snack: Bag of cheese puffs and one cup of apple juice.
- Lunch: Chicken nuggets and two cups of milk.
- Snack: Refused food and took a cup of fruit juice.
- Dinner: A few bites of mashed potatoes and meatloaf along with a cup of milk.

Her mother also reports that Anna will usually take a bottle with milk at bedtime.

Physical Assessment Findings

General appearance: Anna presents awake and alert. She appears well hydrated and well developed, and responds age-appropriately throughout the examination.

Vital signs: Temp: 101.5, Height: 29 in, Weight: 8.19 kg, HR: 128, RR: 36, head circumference 48 cm. Anna plot-

Critical Thinking Case Studies is designed to test your problem-solving and decision-making abilities.

Instructions: Read the symptom(s) above. Then, outline how you would assess and manage the problem. Finally, compare your rationale and decision to that listed in the shaded area.

If you are interested in author guidelines for this column or would like to submit material, contact: Tedra S. Smith, DNP, CRNP, PNP-PC; *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; pnjrn1@ajj.com

ted below the fifth percentile for weight and age, and 10th percentile for length and age.

HEENT: Head normocephalic, intact. Hair evenly distributed. PERRLA noted. Sclerae and corneas clear. Red reflex noted bilaterally. TMs noted clear bilaterally. Nose: Nasal mucosa is edematous, pale and partially obscured by purulent drainage. Trachea: Noted midline. Neck: Full ROM without resistance, no tenderness to touch. No lymphadenopathy noted. Mouth: Moist mucosa membranes without lesions noted. Tongue intact without edema. Uvula midline and mobile.

Integumentary: Warm and dry to touch. No inflammation, no redness, no pus drainage, no tenderness noted.

Respiratory: Symmetric, unlabored expansion. Lungs clear to auscultation. No dyspnea noted.

Cardiovascular: Regular, rate, and rhythm noted. Normal S1 and S2 sounds noted. No murmurs, rub, or gallop noted. Less than 3-second cap refill noted. PMI noted at left midclavicular line over apex. 2+ carotid, radial, and femoral pulses noted.

Abdomen: Abdomen soft and non-distended. No tenderness to touch noted. Abdominal reflex present. No masses or hepatosplenomegaly noted.

Neurological: Speech (two to three understandable words) noted intact. Cranial nerves intact. Gait noted intact.

Musculoskeletal: Full ROM and symmetrical muscle strength noted in all extremities. No edema, no tenderness, no erythema noted over joints. No abnormal spinal curvatures noted.

Genitalia: Tanner Stage I noted. Normal appearance of external genitalia.

Anus: No lesions noted.

Summary

Anna is a 15-month-old female being seen for cold symptoms and decreased food intake. She is awake, alert, and interactive throughout the examination.

Differentials

Gastroesophageal reflux disease (GERD). The backward flow of gastric contents from the stomach into the esophagus. The etiology is unknown and can be a normal process in young, healthy children. Patients will often present with a history of vomit-

ing or spitting up shortly after eating, recurrent diarrhea, and/or questionable abdominal pain and weight loss. GERD is common, and symptoms can begin occurring at any age. Anna did not have a history of overfeeding, no vomiting, and no questionable abdominal pain.

Lead poisoning. Poisoning caused by the ingestion of lead or inhaled through the lungs. Lead poisoning affects children and adults; however, children are more likely to absorb more when exposed than adults (Bowden & Greenberg, 2014). Symptoms may include constipation, anemia, delayed growth, decreased activity level, and abdominal pain. Most poisonings in children occur after ingesting dust chips that contain lead (Burns, Dunn, Brady, Starr, & Blosser, 2013). Anna has not had any change in activity level, no reports of constipation, and lead level was "0" during her 12-month-old well child visit.

Failure to thrive (FTT). A condition in which a person does not consume enough food for adequate nourishment (Ball, Bindler, & Cowen, 2012). FTT can be related to health issues; however, the cause is often not being offered enough food or the unwillingness to eat enough food. In some cases, the child may ingest too many calories through sugary liquid intake and not enough vitamin-rich solid foods. Presenting signs and symptoms may include irritability, weight loss or no weight gain, delayed development, and excessive sleepiness. Anna presented with a decrease in solid food intake and no weight gain. However, Anna's mother did not report any other symptoms related to FTT.

Iron deficiency anemia. A condition caused by poor dietary intake of iron or blood loss (Hay, Levin, Sondheimer, & Deterding, 2011). Iron deficiency anemia in children is commonly related to poor dietary intake. It is seen most often after six months of age due to newborn iron stores being depleted. The most common cause is lack of consumption of an appropriate amount of solid foods. Signs and symptoms are directly related to the amount or lack of iron in the body. Symptoms may include fatigue, pallor, weight loss, tachycardia, and irritability. There may also be a report of blood loss; however, that is usually not the case in young children. Anna presented with a history of cold

symptoms for a few days and a decrease in food intake over the past three months.

Iron deficiency anemia and failure to thrive are both most often related to nutritional intake in infants and young children. Diagnosis is confirmed by the history and physical assessment as well as obtaining a hemoglobin level. Hemoglobin levels between 7 to 10 g/dL are considered mild to moderate iron deficiency anemia (Burns et al., 2013). A serum iron may be drawn if the hemoglobin is extremely low. A diet history provides valuable information related to making the diagnosis and formulating a treatment plan. It is imperative to rule out organic causes prior to confirming it as a nutritional deficiency. Initial treatment includes providing supplemental iron as well as a nutrition plan that may include a feeding schedule.

The Management Plan

Anna was diagnosed with an upper respiratory infection (URI), iron deficiency anemia, and mild failure to thrive. She was prescribed an iron supplement (half teaspoon once daily) and an over-the-counter antihistamine for the URI. Her mother was encouraged to provide Anna with no more than 24 oz. of milk daily and to offer solid foods every three hours. Anna's mother was presented with education on nutrient-rich foods for toddlers, and on the signs and symptoms of increasing severity for each illness. She was encouraged to return to clinic in two weeks for weight check and a repeat hemoglobin study. ■

References

- Ball, J., Bindler, R., & Cowen, K. (2012). *Principles of pediatric nursing: Caring for children* (5th ed.). Upper Saddle River, NJ: Pearson.
- Bowden, V.R., & Greenberg, C.S. (2014). *Children and their families: The continuum of nursing care* (3rd ed.). Philadelphia: Lippincott Williams & Wilkins.
- Burns, C.E., Dunn, A.M., Brady, M.A., Starr, N.B., & Blosser, C.G. (2013). *Pediatric primary care: A handbook for nurse practitioners* (5th ed.). Philadelphia: Saunders.
- Hay, W.W., Levin, M.J., Sondheimer, J.M., & Deterding, R.R. (2011). *Current diagnosis & treatment: Pediatrics* (20th ed.). New York, NY: McGraw-Hills Companies.



The Children's Corner: Perspectives on Supportive Care

Jessika Boles, MEd, CCLS

Life Interrupted: Caring for Young Adult Patients in Pediatric Settings

Jessika Boles

When does adulthood officially begin? Is it at the age of 18, when one becomes a legal adult capable of voting, owning property, serving in the military, and consenting for medical treatment? In today's world, many 18-year-olds are enrolled in college and dependent upon their family's financial resources, medical insurance, and other sources of support to navigate daily life. However, my grandfather was catapulted into adulthood by social circumstance at the age of 16 when he left his home on a Native American reservation in Oklahoma to work as an errand boy for an oil company so he could support my pregnant grandmother. On the other hand, take those who have chosen careers that require many years of post-secondary education – perhaps in the nursing profession! Adulthood, in this case, may not fully begin until the early to mid-twenties when one has completed school and taken a job – therefore defying the legal definition of “adult.”

Biologically, young adulthood, meaning ages 18 to 25 years, is a time in which the brain continues to develop frontal connections that support increasingly complex cognitive functioning (Lebel & Beaulieu, 2011). Cognitively, Piaget and Inhelder (1969) described formal operations as the most complex stage of thought that individuals can develop from exploring their environments; however, they suggested that this stage typically begins in pre-adolescence, around 11 years of age. Socially, and in contrast, institutional structures such as the post-secondary school system, state and federal laws, and cultural beliefs surrounding childbearing, marriage, and family relationships create a spectrum of possibilities for what adulthood can and should look like, as well as its beginning and end.

Perhaps a universal definition of young adulthood cannot yet be created due to the many developmental, biological, and cultural conceptions of the childhood/adulthood dichotomy that currently exist. In the research literature, health care providers have recently turned their attention to this liminal space that young adults occupy not only in

society, but also in the medical setting. It is known that adolescents and young adults experience poorer health care outcomes as a whole than the larger population, specifically those with chronic health conditions (Ferrari et al., 2010). For instance, cancer incidence is increasing more rapidly in individuals 15 to 29 years of age than in younger children or older adults (Zebrack, Mills, & Weitzman, 2007); these patients are also significantly underrepresented in clinical trials (Burke, Albritton, & Marina, 2007). As a result, the young adult population has seen a much lower decrease in mortality rates than other cancer populations (Downs-Canner & Shaw, 2009).

In the case of young adults with type 1 diabetes mellitus, young adulthood is a critical time for imparting self-management skills. This is also the time in which many patients are lost to follow up as they transition from pediatric to adult providers and cope with emerging mental health problems or concerns complicated by geographical, social, and financial role shifts (Anderson & Wolpert, 2004). This time of emergent independence and necessary dependence on insulin and self-care behaviors often predicts long-term morbidity and disease-related complications in the future (Betts, Jefferson, & Swift, 2002). Therefore, young adults with type 1 diabetes mellitus “must negotiate a delicate balance between adhering to a diabetes management regimen and addressing normative developmental tasks” (Luyckx et al., 2008; p. 452). With diabetes and cancer, a discrepancy is typically seen between the developmental needs and concerns of young adults, as well as the services and supports offered in pediatric and adult health care settings. What seems more important is not necessarily the label and location of the environment, but rather, the attentiveness of staff to the unique experiences and beliefs of the young adult population.

Young adults, like any adolescent or adult population, prefer not to be reduced to a simplified set of categories. In fact, young adulthood is the primary time in which 18- to 29-year-olds explore and develop their own sense of identity, their beliefs about the uniqueness of their personality, characteristics, and outlook on life and relationships. Identity exploration can occur through choosing a college

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The Children's Corner: Perspectives on Supportive Care focuses on exploring ways to support children undergoing health-care experiences. Drawing on the documented thoughts and perspectives of children in the research literature, **The Children's Corner** aims to provide practitioners with high-quality evidence-based care practices that also promote the coping and development of children of all ages and their families.

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to attend, career to pursue, where to live, and with whom to work. Young adults begin to experiment with autonomy and independence as they adopt or avoid new responsibilities in the domestic, financial, or social-emotional realms; allegiances may begin to shift from the family to friends and significant others as sources of support when autonomy is not possible or when independence seems too overwhelming. These deepening bonds with others motivate young adults to re-envision their social roles as something larger than themselves – as a companion, a sibling, a child, an employee, a colleague, or a romantic partner. Finally, these relationships then spur the young adult to consider ways to contribute to those they care about, whether through their career path, educational selections, choices of activities, and interaction patterns. Therefore, young adults are deeply invested in goal-setting, personal relationships, autonomy and independence, and developing a sense of self in relation to social roles and personal beliefs (D'Agostino, Penney, & Zebrack, 2011).

Although young adults share some of these common tendencies, all explore their identity in different ways and on varied timelines. For example, I recall recently talking with a newly diagnosed 20-year-old with cancer; his opinion was that this was “probably the best possible time” for his diagnosis because he was living on his own, working a steady job, and enjoying the comforts of family and friends nearby. As he is beginning treatment, I see another patient who is 22 years old and about to celebrate her first wedding anniversary, a 20-year-old young man who is working to combat the effects of his treatment so that he can return to college in the fall, and a 21-year-old who is trying to find his sense of purpose and meaning in life in the advent of his third relapse. Each patient shares a shift from adolescent egocentrism to an outward focus on relationships with family and friends, contributions to society through work and education, beliefs about life and the world, and planning for the future. However, each one explores these domains in different ways and on their own time.

Supports for Young Adults

Disenfranchised by the lack of supports in adult health care settings, more young adult patients with chronic conditions like these are seeking or continuing pediatric care during their early twenties. Based on the developmental goals and needs of this population, more young adult-specific supports are needed in pediatric health care settings

Establishing Open and Accurate Communication

The provider/patient relationship is entirely based on communication; it can be helpful for both patients and providers to explore one another's expectations for the relationship from the very beginning to help promote open communication and trust. Although young adults may still rely on parents to help them with decision-making, they still prefer information that is presented on an adult level, and in an honest, accurate, and sensitive way. It is important for providers to know that young adults may question them at times because this is a developmentally normal behavior. It is crucial to respond to questions and even behaviors without punitive or judgmental language, and in a way that seeks to understand the patient's beliefs, understandings, and motivations (D'Agostino et al., 2011).

Promoting Autonomy

Similar to above, young adults often prefer to be the primary decision-maker in their care, although not always; still, the option should be offered. Language is a primary vehicle for autonomy. Providers should seek to use language that supports what patients *can* do rather than what they cannot, and speak in a way that supports patients' efforts to take on care responsibilities even when they may not be successful in their attempt. This will help promote a lasting sense of self-efficacy or belief in one's self as capable of performing specific tasks. Further, flexibility in scheduling and service delivery can help maximize the young adult's opportunities to experience autonomy across arenas and social roles through work, family, school, and friends.

Involving Peers and Significant Others

First and foremost, it is important to allow young adults to define the important support persons in their lives, and then allow opportunities for these individuals to be involved as much as the young adult would prefer (Zebrack et al., 2007). In addition to valuing these pre-existing relationships, health care facilities should strive to offer young adult-specific support groups, events, and outings with other hospitalized peers when possible. Offering online support networks can also support both social relationships and the patient's sense of autonomy by allowing the patient to control social interactions related to his or her health condition.

Addressing 'Difficult' Topics

Physicians and researchers have identified sexuality, fertility issues, and palliative care services as specifically difficult to discuss with young adult patients and families; however, these topics are of great concern during this developmental period (Quinn & Vadaparampil, 2009; Thomas, Albritton, & Ferrari, 2010). It is important, therefore, to offer honest and open communication about these “difficult” topics when pertinent in the young adult's health care journey; providing peer resources and encouraging support from family and friends can also help the patient make decisions related to these issues. Remember that these are normal topics to discuss and take care to use autonomy-supportive, not punitive or judgmental language, as mentioned above.

Financial and Social Support Services

Finally, young adults represent the current largest and most quickly growing uninsured patient population (Zebrack et al., 2007). Providers should take this into account as a major barrier, not only to accessing care, but also to adherence and follow-through among young adult patients (Anderson & Wolpert, 2004). It is important to partner with social workers, case workers, and other social support professionals to help young adult patients transverse these very real social and financial barriers that hinder access to and motivation to pursue health care.

Conclusion

In conclusion, young adults with a chronic illness “occupy a sort of no-man's land,” caught between the models of the adult and pediatric health care worlds and without a home in between (Ferrari et al., 2010, p. 4850). At the same time, young adults can succeed in medical care and self-management regardless of environment when they are given sup-

ports that encourage open and accurate communication, promote their sense of autonomy, and incorporate important social relationships with peers and family as the young adult explores difficult topics and attempts to access community resources. We were all young adults once, full of wonder and possibility, pining for independence and intimacy. Through communication, emotional support, and attentiveness to the developmental challenges of young adulthood, our patients can experience the same outcomes regardless of the limitations of their chronic illness. ■■

References

- Anderson, B.J., & Wolpert, H.A. (2004). A developmental perspective on the challenges of diabetes education and care during the young adult period. *Patient Education and Counseling, 53*, 347-352.
- Betts, P.R., Jefferson, I.G., & Swift, P.G. (2002). Diabetes care in childhood and adolescence. *Diabetic Medicine, 19*, 61-65.
- Burke, M.E., Albritton, A., & Marina, N. (2007). Challenges in the recruitment of adolescents and young adults to cancer clinical trials. *Cancer, 110*(11), 2385-2393.
- D'Agostino, N.M., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer, 117*(Suppl. 10), 2329-2344.
- Downs-Canner, S., & Shaw, P.H. (2009). A comparison of clinical trial enrollment between adolescent and young adult oncology patients treated at adolescent and young adult (AYA) oncology patients treated at affiliated adult and pediatric oncology centers. *Journal of Pediatric Hematology/Oncology, 31*(12), 927-929.
- Ferrari, A., Thomas, D., & Franklin, A.R., Hayes-Lattin, B.M., Mascarin, M., van der Graaf, W., & Albritton, K.H. (2010). Starting an adolescent and young adult program: Some success stories and some obstacles to overcome. *Journal of Clinical Oncology, 28*(32), 4850-4857.
- Lebel, C., & Beaulieu, C. (2011). Longitudinal development of human brain wiring continues from childhood into adulthood. *The Journal of Neuroscience, 31*(30), 10937-10947.
- Luyckx, K., Seiffge-Krenke, I., Schwartz, S.J., Goossens, L., Weets, I., Hendrieckx, C., & Groven, C. (2008). Identity development, coping, and adjustment in emerging adults with a chronic illness: The sample case of type 1 diabetes. *Journal of Adolescent Health, 43*, 451-458.
- Piaget, J., & Inhelder, B. (1969). *The psychology of the child*. New York, NY: Basic Books.
- Quinn, G.P., & Vadaparampil, S.T. (2009). Fertility preservation and adolescent/young adult cancer patients: Physician communication challenges. *Journal of Adolescent Health, 44*, 394-400.
- Thomas, D.M., Albritton, K.H., & Ferrari, A. (2010). Adolescent and young adult oncology: An emerging field. *Journal of Clinical Oncology, 28*(32), 4781-4782.
- Zebrack, B.J., Mills, J., & Weitzman, T.S. (2007). Health and supportive care needs of young adult cancer patients and survivors. *Journal of Cancer Survivorship, 1*, 137-145.



Demystifying Research

Jean Ivey, PhD, CRNP, PNP-BC, FAANP

The Value of a Pilot Study

Jean Ivey

Early in our education we are taught that new ideas and experimentation are valuable and important. However, when new ideas drive actions without thorough investigation and evaluation, the results may be disastrous rather than enlightening. So researchers investigate ideas and study the concepts involved. They try and reject multiple models to gain some understanding about the factors involved and how they interact. Finally, they decide how to test the model they think is most likely to fit the concepts they have identified. A pilot study is usually the next step. It might be to test one or more components of the model or a representation of the concepts they are studying. For example, if I wanted to make the perfect diaper, I might think hypoallergenic materials, disposability, retention of urine and/or feces between changes might be important, and construct a diaper that includes those features. However, if upon testing those on three children I find out the diaper leaks eight times out of 10, and parents said it was ugly and hot, I know I must redesign it. Had I released the first version to the public, my sales would plummet after the initial sales.

Over the past decade, there has been awareness of the issues related to chronically ill adolescents who must transition to adult health care providers and systems (Klassen et al., 2014; Middleton et al., 2014; Schwartz et al., 2014). As noted in other groups of chronically ill persons, impaired mobility and stigma related to the illness may isolate the adolescent from resources other teens can easily access. This may prevent the chronically ill adolescent from having the information and support needed to make the transition to adult care.

The May-June 2014 issue of this journal featured an article about provider perceptions about this process (O'Sullivan-Oliveira, Fernandes, Borges, & Fishman, 2014). Issues raised included the importance of transition, setting boundaries for the time of transition, patient and provider emotional attachments, institutional support, and resource availability. An additional concern for many young people with impaired mobility is unwanted weight gain and obesity. Some have suggested that the time spent on the Internet,

Review of:

Betz, C., Smith, K., Marcias, K., & Bui, K. (2014). Exploration of Internet use: Profile and preferences of transition-aged adolescents with spina bifida. *Pediatric Nursing, 40*(4), 173-178.

mobile phones, and electronic games has caused weight gain in children and adolescents.

Betz, Smith, Macias, and Bui (2014) investigated the usefulness of an intervention based on young people's interest in visual media. They decided to use the time teens spent online as a communication and education tool for one diagnostic group of teens, which is probably applicable to other groups. Although they found there was a high rate of Internet use, they also found far fewer participants who had used the Internet to get information about their disorder or to contact other teens with the same health care issues. Obviously, health care providers want their patients to get more information about their diagnosis and treatment. Betz and colleagues (2014) also thought that most teens communicated with peers via the Internet and might receive social support in this manner.

The investigators conducted a thorough review of the literature to find other studies about teen Internet use, including the purpose of searches, gaming, use of social media, barriers, and facilitators for this group. Some concerns from the literature were that the possibly lower literacy level and educational level of the adolescents might make it difficult for them to interpret information they received online. An unguided search on even some common chronic diseases might produce few results.

Based on the literature and their clinical and research experience, the investigators developed a short survey to pilot with about 50 adolescents to see if the general characteristics reported in the literature applied to their group. This gave them an opportunity to test the intervention they thought could be expanded to a larger group or other diagnostic group participants or for other purposes. Their observations about the results will allow them to refocus their study and make changes in the approaches they will take. An important finding concerning the isolation of chronically ill adolescents may lead to further investigations.

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Demystifying Research

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Pilot studies require extra time and work, and are usually not funded. On the positive side, they enable a researcher to learn important things, such as whether or not recruitment strategies are likely to be successful, and to discover unexpected barriers to consent, data collection, or other steps in the process. They also allow the researcher to establish contacts and a network of other professionals who will help with the full study. ■■■

References

- Betz, C., Smith, K., Marcias, K., & Bui, K. (2014). Exploration of Internet use: Profile and preferences of transition-aged adolescents with spina bifida. *Pediatric Nursing, 40*(4), 173-178.
- Klassen, A.F., Rosenberg-Yunger, Z.R., D'Agostino, N.M., Cano, S.J., Barr, R., Syed, I., ... Nathan, P.C. (2014). The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults. *Health Expectations*. Advance online publication. doi:10.1111/hex.12241.PMID:25052198
- Middleton, P.G., Matson, A.G., Robinson, P.D., Jane Holmes-Walker, D., Katz, T., & Hameed, S. (2014). Cystic fibrosis related diabetes: Potential pitfalls in the transition from paediatric to adult care. *Paediatric Respiratory Reviews*. Advance online publication. pii: S1526-0542(14)00074-8. doi:10.1016/j.prrv.2014.05.003. PMID:24973264
- O'Sullivan-Oliveira, J., Fernandes, S., Borges, L., & Fishman, L. (2014). Transition of pediatric patients to adult care: An analysis of provider perceptions across discipline and role. *Pediatric Nursing, 40*(3), 113-120; 142.
- Schwartz, L.A., Daniel, L.C., Brumley, L.D., Barakat, L.P., Wesley, K.M., & Tuchman, L.K. (2014). Measures of readiness to transition to adult health care for youth with chronic physical health conditions: A systematic review and recommendations for measurement testing and development. *Journal of Pediatric Psychology, 39*(6), 588-601. doi: 10.1093/jpepsy/jsu028.