PEDIATRICS, CHILD AND ADOLESCENT HEALTH

CHILDREN AND CHILDHOOD

SOME INTERNATIONAL ASPECTS

PEDIATRICS, CHILD AND ADOLESCENT HEALTH

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CHILDREN AND CHILDHOOD

SOME INTERNATIONAL ASPECTS

JOAV MERRICK
EDITOR

New York

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Chapter 1

CHILDREN AND CHILDHOOD

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Just a few decades ago, children born with significant congenital anomalies or genetic and metabolic diseases perished at an early age and very few survived into their teens and even less into adulthood. Congenital heart disease, major errors in metabolism, cancer, cystic fibrosis and many other major diseases were fatal. Because of that many physicians in adult primary care did not have the opportunity to see patients with these problems and thus were unable to learn how to care for them. With major advancements in medical knowledge, technology, imaging techniques, surgical skills and pharmaceutical products as well as prosthetic devices, many of these patients now live much longer life and sometimes even close to the average life expectancy for the country at least in the developed world. With that, a new medical care challenge has been created and we have to take a life span approach.

INTRODUCTION

Before birth through young adulthood there is a wide range of health issues that affect our children, such as general childhood illnesses, eating and obesity, accidents and injuries, and

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particular stages of life, such as teenage independence. Child health and pediatrics focus on the well-being of children from conception through adolescence, but human development is a life span issue, so research in childhood does not stop with the end of adolescence, but we need a long-term and lifelong study to observe and understand the development process. Pediatrics is vitally concerned with all aspects of children's growth and development and with the unique opportunity that each child has to achieve their full potential as a healthy adult.

Pediatrics was once not a specific entity, just as adolescence really did not exist as a concept, since all was a part of adult medicine. This field emerged in the 19th and early 20th century as a medical specialty, because of the gradual awareness that the health problems of children were different from those of adults and children's response to illness, medications and the environment is very depending upon the age of the child.

This uniqueness of children, along with diseases that are particular to this age group, has been responsible for the development of pediatrics as a specialty and for the creation of children's hospitals for the care of children.

CHILD HEALTH RESEARCH

These same factors have also driven the creation of child health research, but we are still only able to do a few large lifelong studies to see the effects of pregnancy or early childhood on health and well-being in adulthood and older age. Long-term birth cohort studies have been and are conducted in the United Kingdom under the auspices of the Centre for Longitudinal Studies in London, like the National Survey of Health and Development (NSHD) established in 1946, the National Child Development Study (NCDS) established in 1958, the 1970 British Cohort Study (BCS70) and the Millennium Cohort Study (MCS) established in 2000 (1). In Denmark with the Copenhagen Perinatal Birth Cohort of 9,125 individuals born 1959-1961 at the maternity departments of the Copenhagen University Hospital, Rigshospitalet (2) and the Danish National Birth Cohort 1996-2002 of 101,042 pregnant women recruited in first trimester at first antenatal visit at the general preactitioner with 96,986 children resulting from the pregnancies (3). In the United States the National Institute of Child Health and Human Development has recently also intitiated a large prospective life-history study, the National Children's Study, examining the effects of the environment and genetics on the growth, development, and health of children with more than 100 000 children who will be followed up from conception to age 21 years (4).

Such cohort studies of child health and human development over the lifespan are very important for our understanding of trends in health and well-being, quality of life and quality of care, which will reveal emerging of "new morbidities" as we have seen over the past 50 years in pediatrics (5), but such cohort studies are very expensive, huge logistics involved and not always possible to conduct.

GROWTH AND DEVELOPMENT

A healthy development begins before conception with parental health and their genetic composition and continues on to conception and through the prenatal period. Once delivered, new issues emerge, such as breastfeeding, newborn screening tests, health care appointments and immunizations. Development constitute a continuum and a child changes amazingly during the neonatal, newborn period and early infancy. During this period there are many challenges both for the child, the parents and the family and before you know it the child enter adolescence and adulthood.

CURRENT ISSUES

CS Mott Children's Hospital at the University of Michigan in Ann Arbor conducts a National Poll on Children's Health in order to monitor the future. In their collaboration with Knowledge Networks in this nationally representative household survey they administer to a randomly selected, group of adult with and without children of about 2,000 person that closely resembles the United States population. In 2010 the following overall health concerns for US children in 2010 and the percentage of adults who rate each as a "big problem" included (6):

- Childhood obesity, 38 percent
- Drug abuse, 30 percent
- Smoking, 29 percent
- Internet safety, 25 percent
- Stress, 24 percent
- Bullying, 23 percent
- Teen pregnancy, 23 percent
- Child abuse and neglect, 21 percent
- Alcohol abuse, 20 percent
- Not enough opportunities for physical activity, 20 percent
- Chemicals in the environment,18 percent
- Sexting,16 percent
- Depression, 15 percent
- Sexually transmitted infections, 15 percent
- School violence, 13 percent
- Asthma. 10 percent
- Neighborhood safety, 8 percent
- Autism, 8 percent
- Suicide, 8 percent

But the perception of the parent does not always portray the view of the child and researchers have therefore become concerned with the children's own perception of health. One study from Portugal (7) used creative drawing language the identify external factors perceived as negative or positive to health by children. The sample consisted of 130 children in 3rd and 4th classes from four randomly selected schools found that children value healthy food, physical activity, mental health, prevention of inappropriate substance consumption and health and environment. The drawings and comments showed links between diet and physical exercise, and between mental health and interpersonal relationships (7).

> "We cannot always build the future for our youth, but we can build our youth for the future." Franklin D Roosevelt (1882-1945)

CONCLUSION

Just a few decades ago, children born with significant congenital anomalies or genetic and metabolic diseases perished at an early age and very few survived into their teens and even less into adulthood. Congenital heart disease, major errors in metabolism, cancer, cystic fibrosis and many other major diseases were fatal. Because of that many physicians in adult primary care did not have the opportunity to see patients with these problems and thus were unable to learn how to care for them.

With major advancements in medical knowledge, technology, imaging techniques, surgical skills and pharmaceutical products as well as prosthetic devices, many of these patients now live much longer life and sometimes even close to the average life expectancy for the country at least in the developed world. With that, a new medical care challenge has been created and we have to take a life span approach.

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SECTION ONE: INTERNATIONAL ASPECTS ON CHILDREN AND CHILDHOOD

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Chapter 2

COMBINING BREAST MILK AND FORMULA

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This chapter explores black women parents' motivation for, and views on, combining breast milk and formula in infant feeding and the impact of this practice on their infants' health. The study uses aspects of grounded theory and the phenomenological approach in data collection and analysis. The research was conducted in Indiana, and data were collected by the first author and a research assistant. Twenty-five mothers were included in the study. Three themes emerged from the data: 1) breastfeeding problems at home and in the community, 2) engorged breasts and 3) children with low birth weight. The findings of this study show that providing breastfeeding education in communities, along with encouragement from health professionals and family members, is crucial for increasing the likelihood that mothers will exclusively breastfeed.

INTRODUCTION

Many researchers have noted a deep ambivalence among mothers regarding the feeding practices of infants. A social-ecological framework that takes note of all the cultural, social, and personal circumstances of mothers may be helpful in explaining why some women choose to supplement breastfeeding with formula and others do not. As qualitative studies demonstrate, social context, family support, and more specific information on how to deal with the early challenges of breastfeeding may play a large role in mothers overcoming ambivalence about breastfeeding (1-4).

An interesting observation is that even in demographic groups with high rates of breastfeeding initiation, mothers continue to supplement breastfeeding with formula. Hispanic women have met one of the Healthy People 2020 breastfeeding initiation goals, with about 80% initiating breastfeeding (5), yet they also have proportionally higher rates of formula supplementation (6). Similar rates of formula, combined with relatively high rates of

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breastfeeding initiation, have been noted in other social and ethnic groups, including Native American women (7).

Some mothers rely on their interpretations of their infants' feeding cues and anxieties, and on their own uncertainties about nutrition through breastfeeding, believing that crying means the infants are not getting enough breast milk, leading mothers to supplement it with formula (8). Often, family members shared these concerns and encouraged supplementation, which may suggest that the mothers' lack of self-efficacy results in feeding decisions more influenced by their immediate social network than by beliefs or by advice from lactation educators (8, 9).

In a study of young, low-income mothers in an urban area, several mothers who supplemented breastfeeding with formula reported a cycle of increased breastfeeding, followed by breast engorgement and pain, leading to a suspension of breastfeeding until the engorgement subsided, resuming the practice of complementary feeding (3). However, such instruction in breastfeeding—and its impact on the intention to breastfeed—may account for little in mothers' continuation of breastfeeding for longer than the first week after birth (10). More education regarding feeding practices may be a start, but it does not necessarily address the complex social, cultural, and personal circumstances that new mothers face (3, 8). Interventions to encourage women to breastfeed exclusively should focus on every aspect of the breastfeeding process, instead of just on health benefits or mechanics. Oftentimes, advice given to mothers about infant feeding practices, which encourages formula supplementation, runs counter to the physiological mechanisms of breastfeeding (11).

In view of the above literature, there is an urgent need for the promotion of exclusive breastfeeding, which takes into account all of the aspects of breastfeeding for the first six months of children's lives to give them a healthy start. The aim of this research, therefore, is to examine various strategies that encourage mothers to breastfeed exclusively, in order to make recommendations that could encourage mothers to exclusively breastfeed infants for the first six months.

OUR STUDY

This study comprises a qualitative survey with a quantitative component designed for black women regarding their views on supplementing breast milk with formula. The Indiana University Institutional Review Board approved the study. Potential participants in the study were contacted through email, phone calls, and, where possible, in person by the principal investigator and research assistants. The criteria for participating in this research included being a black woman and a mother. Potential participants were notified that taking part in the study was voluntary. It took about twenty-five minutes for each participant to complete the questionnaire used in the study. Completed questionnaires were hand-delivered or sent through e-mail to the researchers.

The data collection instrument contained a list of eight questions. These questionnaires were composed of open-ended and closed-ended questions and were distributed to participants in person and by email.

The areas assessed included participants' views on, and motivation for, supplementing breast milk with formula and also inquired about their experiences using both breast milk and formula. The questionnaire was pilot-tested with 10 participants to insure that the wording and the content were appropriate for the participants. Participants in the pilot study were not asked to take part in the main study, since the same questions were used in both the pilot and this main study.

The phenomenological approach was used as one of the tools for data analysis (12, 13). Twenty-five participants took part in the study. Polkinghorne (14) recommends a sample size of 5 to 25 for a phenomenological study, thus making the use of 25 participants for this study appropriate. The study also uses aspects of the grounded theory framework, which entails drawing comparisons and noting differences between participants' utterances.

The data were coded by the lead author and a paid research assistant. Data from the open-ended questions were used for the qualitative aspect of the research. Because this study used grounded theory and the phenomenological approach, the data coding began with open coding where the coders looked for similarities in participants' utterances and compared them. During the comparison process, newly identified analytic categories were grouped with already identified categories, and those identified as different, which did not belong to an already identified category, were placed in different analytical categories (15). The phenomenological approach also allowed the researchers to describe participants' personal experiences during the feeding of their infant (12, 13, 16). In addition to the establishment of themes, the data analysis also involved the explication of thematic characteristics.

FINDINGS

Twenty-one (84%) of the participants indicated that their education as high school–level or below. Three (12%) participants indicated having taken some college courses. One participant indicated having a bachelor's degree. The majority of participants indicated that they had part-time jobs and were taking classes. Only 4 indicated having a full-time job.

Three themes emerged from the written comments obtained by the investigators: 1) breastfeeding problems at home and in the community, 2) engorged breasts, and 3) children with low birth weight. Table 1 below illustrates a thematic summary of the participants' responses about breastfeeding and formula.

Exclusive breastfeeding problems at home and in the community

The literature on exclusive breastfeeding indicates that breastfeeding is known to help cut down childhood diseases, therefore making breastfeeding an important preventive approach to help reduce infant mortality (17-20). Exclusive breastfeeding, according to the Lancet series, showed a success rate of 13% in reducing infant mortality rates. However, despite the numerous advantages of breastfeeding, only 39% of babies are exclusively breastfed worldwide (21). The reasons for this low breastfeeding rate, as documented by scholars, include a delay in the initiation of breastfeeding after childbirth, a lack of resolving breastfeeding difficulties, and giving fluids to the baby, among other reasons (22).

Table 1. Participants, theme and group summary

Participants	Theme	Group Summary
18 (72%)	*Breastfeeding feeding problems at home and in the community*	Participants in this group believed that their children were not getting enough breast milk. The mothers in this group reported that exclusive breastfeeding will take all their time, leaving no time for them, their work/school work and family. Mothers reported that nobody in their community will breastfeed in public and there were not many places to breastfeed their babies in the community.
4 (16%)	*Engorged breasts*	Participants reported that having engorged breasts was painful and contributed to their combining of breastfeeding with formula.
3 (12%)	*Children born with low birth weight/preterm*	Participants in this group believed that the weight of their infants was so low that breast milk alone was not enough for their child.

In the current research, parents' reasons for supplementing breastfeeding with formula instead of exclusively breastfeeding included concerns about there being insufficient milk, about having enough time for themselves, their school work, and the rest of the family, and about a lack of acceptability of exclusive breastfeeding in the community. This is what participants wrote:

> "My child barely got some milk during breastfeeding and I was afraid the milk I was producing was not enough for her."
>
> "I can't imagine myself doing breastfeeding alone; there will be no time left for me to do anything."
>
> "Lack of acceptability by the community on breastfeeding in public had an influence on me to breastfeed at home and to use formula when I'm outside."

Breast problems

Pain during breastfeeding may also lead women to supplement with formula. Scholarship on infant feeding indicates that the discontinuation of breastfeeding may be due to breast problems such as breast abscess and mastitis. Breast abscess and mastitis are frequently reported among breastfeeding mothers (23). Depending on the participants and where the study took place, breast abscess and mastitis may occur between 2% and 33% of nursing mothers (23).

Participants (4) in this research reported that engorged breasts were painful and contributed to their combining of breastfeeding with formula. One participant wrote the following:

> "I was going through a lot of pain that I just couldn't continue breastfeeding and my next option is [sic.] to give him formula and breastfeed when I was not in pain."

Children born preterm with low birth weight

Parents with low-birth-weight children face many problems. These problems may include concerns about the overall health of their child, how to breastfeed the low-birth-weight child, or the lack of knowledge about support systems available for the parents and their child (24-28). In this research, the parents' main reason for using breast milk and formula was the low weight of their infant.

One participant wrote:

> "I thought the only way to increase my child's weight and for her to survive was to breastfeed her and use formula."

> Another participant said: "I have never seen any child with such a low birth weight in my life, my parents and grandparents had many children but they told me they never had a baby with such a low birth weight. My only option, I thought, was to give formula to increase my child's weight."

Interpretations and significance of study

This study was designed to offer information about the simultaneous use of formula and breastfeeding. The study has shown that some of the mothers' reasons for using formula (e.g., not having sufficient milk), and hence not exclusively breastfeeding, could be solved by mothers breastfeeding on demand and not on schedule. Proper latching and proper positioning of the baby during breastfeeding will also help solve some breastfeeding problems, including the baby not getting sufficient milk.

Based on this study's findings, providing a family- and community-centered approach in educating and supporting mothers at home and in their communities will help promote exclusive breastfeeding.

In addition, the incorporation of the mothers' comments and problems into training programs, such as peer support groups training, will be relevant for future practices of breastfeeding professionals.

Concerning a reported lack of time and inability to breastfeed their baby, mothers could pump breast milk, and family members could help with the feeding of the baby while the mother is at work or school.

The strength of this research is that it asked mothers to provide reasons for supplementing the nursing of their babies with formula. However, since some mothers did not answer all 8 research questions, the study findings may not reflect the views of all of the mothers who took part in this study. No attempts were made to follow up with participants when some survey questions were not answered because of the anonymous nature of this research.

Research indicates that babies who are born preterm do well with their mothers' milk rather than any other infant foods (29). In view of the above research findings, and based on the findings in the current study, it is recommended that mothers be encouraged by family members and the community to exclusively breastfeed. There is no doubt that breastfeeding helps to reduce the incidence of many childhood diseases and consequently helps to reduce healthcare costs. Appropriate attention to exclusive breastfeeding is good for a baby's health and must attract the attention of all of the stakeholders in an infant's health.

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Chapter 3

RURAL COMMUNITY-BASED MATERNAL AND NEWBORN INTERVENTIONS ON PREVENTION OF NEONATAL MORALITY

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In this chapter we aimed to examine the effect of a community-based maternal and newborn interventions which include mother's knowledge of pregnancy, delivery, post-partum and newborn complications, care seeking behaviour and newborn health practices on neonatal mortality in rural Uttar Pradesh, India. Data came from a household survey conducted to evaluate a community-based maternal and newborn intervention program in two districts of Uttar Pradesh, India. Analysis included data from 13,612 recently delivered women who had a singleton live birth during 2004-2005 at home. Neonatal mortality was 23% lower among mothers who had better knowledge of pregnancy and delivery related complications (OR:0.77; 95% CI:0.57-1.04;p = 0.090) than who had a poor knowledge; almost half among mothers who fed colostrums to their newborn

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(OR:0.54; 95% CI:0.40-0.73; p < 0.0001), who provided complete thermal care (OR:0.65; 95% CI:0.50-0.84; p = 0.0001), among mothers who received two or more doses of TT injections (OR:0.80; 95% CI:0.62-1.04) and among the newborns whose mother attained high school and above education (OR:0.56 ;95% CI:0.37-0.86; p < 0.0001) than their counterparts. However, the likelihood of neonatal mortality was almost twice (OR:1.87; 95% CI:1.33-2.61;p < 0.0001) among the newborn whose birth interval was less than 18 months. Our study suggests that most of the neonatal deaths in rural India can be preventable if mothers have better knowledge of pregnancy and delivery related complications, and had 'preventive' rather than 'curative' newborn health care practices at the community level. Intervention program should focus more on the spacing methods for optimum birth interval, colostrum feeding along with improving mother's knowledge of complications.

INTRODUCTION

The neonatal period is recognized as a brief, critical time that requires focused interventions to reach the Millennium Development Goal (MDG) of a two-thirds reduction in child mortality by 2015. In spite of decline in global under-five and infant mortality rates during the recent decades, newborn mortality rate has remained relatively high (1, 2). In India there are one million neonatal deaths every year, representing approximately a quarter of all global neonatal deaths (2, 3). Neonatal deaths account for about 38% of the annual 10.6 million child deaths recorded worldwide and nearly half of the deaths in children under 5 years in India (1, 2). Two-thirds of infant deaths in India occur in the first month of life, and three-fourths of newborn deaths occur in the first week of life (1). Two-thirds of all births and three-fourths of births in rural areas of India take place at home. Untrained providers attend nearly 60% of all births (1).

Most neonatal deaths in developing countries are associated with prematurity, maternal neglect and also complications of pregnancy, delivery and the postnatal period (4-6) and the majority of these deaths are thought to be preventable through standard antenatal, intrapartum and postnatal care (7) and mother's knowledge about pregnancy complications, delivery complications, postpartum complications and essential newborn care practices. Care practices immediately following delivery contribute to newborns' risk of morbidity and mortality (5, 7-9). Knowledge about newborn care practices comprises of cutting and tying the umbilical cord aseptically, drying and wrapping the newborn promptly to prevent hypothermia, breastfeeding and seeking care immediately for signs of serious newborn illnesses. Clean cord care, thermal care and breastfeeding have been identified as proven interventions that save newborn lives (6-7, 9-11). However, few community-based studies have examined these care practices and their association with neonatal mortality and also community-based data from developing countries are scarce (12-15).

Research conducted in low and middle income countries (LMICs) suggest that high coverage of a few simple and cost-effective interventions would reduce neonatal mortality (7, 16-18). Interventions at the family and community level can save lives, especially where health systems are weak (19, 7). Several community-based efficacy trials have evaluated service delivery strategies to improve newborn survival (11, 15, 20). However, population-level data on the impact of mother's knowledge of pregnancy, delivery, postpartum and new born complications and family and community-based neonatal care on neonatal mortality from large-scale programme is scarce. Here, we examined the effect of a community-based maternal and newborn interventions on neonatal morality in rural Uttar Pradesh, India.

OUR STUDY

This study used data from a large cross-sectional household survey conducted between January and March 2006 to evaluate a community-based intervention program known as the Integrated Nutrition and Health Programme (INHP) in two rural districts of the state of Uttar Pradesh (UP) in India. A quasi-experimental design was used and the study design, data collection and analysis were conducted by a team of independent researchers who were not involved in the implementation of the intervention. One INHP district namely Barabanki (UP), served as the intervention district, while a district receiving standard government health and Integrated Child Development Services (ICDS), Unnao, was used as a comparison district. From the 15 rural blocks in each district, we used a computer program to randomly select nine blocks in the intervention district and eight blocks in the comparison district (the difference in the number of blocks selected was due to differences in population size of the blocks in Barabanki and Unnao). One sector, an area with 15-25 *Anganwadi* workers (village-based workers) and an estimated population of 20000 to 25000 people, was randomly selected from each of the selected blocks. The sample size was calculated to detect a 20% reduction in neonatal mortality following the intervention with 80% power at a 5% significance level. The details of the intervention, the study design and the data quality assurance methods were presented elsewhere (21). The study documented some improvements in essential newborn care practices in the intervention area relative to the comparison area but measured no change in neonatal mortality (21).

Mapping and listing exercises resulted in selection of 61,836 households and a complete enumeration of all households was done with a response rate of 95.9% (n = 59,278). From the above households 56,375 women were found to be between 15-49 years old. A complete pregnancy history of 52,187 women (a response rate of 92.6%) has been done to identify women that had a live birth or stillbirth during the two and half years preceding the survey. Ultimately 17,317 women were identified and interviewed. Data on pregnancy outcomes, survival status of all singleton live births infants, care received during pregnancy, delivery, and the postnatal period and socio-demographic characteristics were collected from 13,612 women who gave birth during the years 2004-2005.

Data were collected to establish levels of maternal and newborn care practices for a community-based intervention program. Women were asked detailed questions about the care they received during pregnancy and delivery, their newborn care practices at home along with the socio-economic characteristics of the household. In addition, information about all pregnancies and pregnancy outcomes (live birth, still birth and spontaneous or induced abortion) was collected, including the date of each outcome. The status of each live born baby was noted, and if a baby was reported dead, the age at death was recorded.

From each woman, detailed information was gathered on knowledge and practices related to antenatal period, delivery, postpartum period and newborn care. It recorded levels of coverage for antenatal, delivery, postpartum and newborn services referring to the women's last pregnancy. Antenatal questions asked about the essential care received during pregnancy, birth complications and their management. Delivery care questions focused on safe delivery practices, problems experienced and their management. Questions about postpartum care included the appropriate timing and frequency of care. Questions about immediate newborn care included management of the umbilical cord, baby weighing, bathing and wrapping of the newborn, and breastfeeding. Questions about newborn care during the first month of life asked whether the newborn received a check-up and who conducted it, cord care practices, thermal care, breastfeeding practices and illnesses experienced by the newborns and treatments for them.

For the estimation and analysis of differentials in the levels of mortality among the neonates, we have extracted only those women that had their recent live birth during 2004-2005. We have excluded the births before 2004 to avoid the longer period recall laps and also to avoid the seasonality including an incomplete birth year for mortality analysis. Also the maternal and child health care and behavioral information are available only to recently births. In the present paper neonatal mortality analysis is based on a total of 13,612 singleton live births of women. The pregnancy losses, stillbirths and multiple births have been excluded from the analysis.

The information collected are known to be of better quality and are expected to derive the major causal factors associated with differential in the neonatal mortality. Further, while studying the mortality experiences of the newborns, the completeness of birth and death information is vital. However, this data gives quality information on these aspects. An independent data quality assurance was conducted on 5% of the sample and matched periodically. Data were entered twice by independent data operators, then matched and checked for internal consistency. The study received ethical approval from the Johns Hopkins University Committee on Human Research and the King George Medical University ethics committee. Informed consent was also obtained from each respondent before the interview.

It is important to use an appropriate procedure to calculate the level of neonatal mortality and to study the various associated factors. It also emphasizes the importance of proper controls for understanding the independent effect of each of the covariates. Hence, we have used a number of variables, which have either a direct or indirect effect on experiencing a neonatal death. Explanatory variables included in this paper are socio-economic and demographic characteristics of the mother, level of mother’s knowledge of pregnancy complications, newborn complications, actual pregnancy and delivery complications and assistance by trained provider, and community-based maternal and newborn health care practices and study area. Among the socio economic variables, mother’s education, caste and religion have been included. Economic status has been captured through measuring wealth quintiles using asset approach. Demographic and reproductive behaviour included mother’s age at the most recent birth, newborn’s sex, birth order, birth interval for the most recent child and status of the previous pregnancy outcome. Programmatic variables which have been examined in this study are mother’s knowledge of pregnancy, delivery, post-partum and newborn complications, antenatal practices, status of tetanus toxoid (TT) injections and intake of iron and folic acid (IFA) tablets, delivery status and mother’s care seeking behaviors. The study also includes newborn care practices such as cord care, thermal care, breastfeeding and newborn care seeking behaviour which has been identified as affecting neonate’s survival.

Wealth quintiles have been computed based on different household durable goods by factorial analysis. The items for factorial analysis are similar to the NFHS-3 used for computation of wealth index (22). Mothers knowledge of pregnancy, delivery, postpartum and total knowledge score has been computed and presented in three categories as poor, average and better based on mean and SD.

First, bi-variate analysis has been done to compute neonatal death. A neonatal death was defined as a live born child who died before 28 days of age. Neonatal mortality rates were calculated as the proportion of neonates who subsequently died within a given time frame and expressed per 1000 live births (during the year 2004-2005) and presented with 95% confidence intervals (95% CI). Also Pearson's chi-squared tests were performed to compare the levels of neonatal mortality within the socio-economic and demographic and maternal and newborn health care practice. Lastly, multiple logistic regression models has been applied to assess the determinants of neonatal mortality and results are presented as odds ratios (OR) and 95% CI. Data analysis was conducted with Stata 10 (StataCorp. LP, College Station, TX, United States of America).

FINDINGS

Table 1 presents percentage distribution of selected socio-economic, demographic and maternal and child health care characteristics and their association with neonatal mortality in rural Uttar Pradesh during 2004-2005. The study population primarily consists of younger women (mean age 25.4 years ± 6.48 SD). More than 40% of the mothers had a birth order 4 and above and majority were illiterate (68%). Most of the women were Hindu and higher proportion were from other backward class (46%) followed by Scheduled caste/tribes (42%). One in every four women belonged to a poorer wealth quintile household.

A total of 621 neonatal deaths were recorded and the neonatal mortality rate (NMR) per thousand live births was 45.6 (95% CI:42.2-49.9). NMR was relatively higher among mothers whose age at most recent birth was either in teen age (55.8/1000; 95% CI:46.8-66.0) or more than 30 years (48.6/1000; 95% CI:41.5-56.6), illiterate, Hindu, scheduled caste/scheduled tribes, and among those who belonged to the lowest wealth quintile. Also NMR was notably higher in the 1st or higher birth order (6+) and among the birth interval of less than 2 years (72.0/1000; 95% CI:57.3-89.0). Also NMR was significantly higher among mother's who had a newborn death in previous birth (85.6/1000;95% CI:70.1-103.3).

Mother's knowledge of pregnancy, delivery and postpartum complications and health care practices and associated neonatal mortality.

Table 2 shows the status of mothers' knowledge of complications and care-seeking behaviors and their association with neonatal mortality. NMR was significantly higher among mothers who have poor knowledge about pregnancy, delivery and postpartum complications (48.8 vs. 38.8; p = 0.083), newborn complications (48.6 vs. 42.8; p = 0.497) and all complications mentioned above (49.6 vs. 38.7; p = 0.130) than mother who had better knowledge. NMR was relatively higher among women who went for curative care ("pregnancy complication and Antenatal care" (ANC) compared to those who went for routine care ("no complication and ANC") (54.7 vs. 38.2; p = 0.004). NMR was significantly lower among women who consumed adequate IFA tablets than those who had not consumed IFA tablet (42.6 vs. 48.5).

Table 1. Status of socio-economic, demographic characteristics and their association with neonatal mortality in rural Uttar Pradesh, India, 2006

Selected characteristics	All Singleton Live Births		Neonatal Mortality			χ^2 p value
	Number	Percent	Number	Rate	(95% CI)	
Mother's age at most recent birth						p = 0.010
Less than 20 years	2,293	16.9	128	55.8	(46.8-66.0)	
20-29 years	8,075	59.4	336	41.6	(37.4-46.2)	
30-49 years	3,230	23.8	157	48.6	(41.5-56.6)	
(Mean: 25.4 & SD ± 6.48)						
Mother's education						p = 0.116
Illiterate	9,210	67.7	435	47.2	(43.0-51.8)	
Literate, < middle school complete	1,887	13.9	91	48.2	(39.0-58.9)	
Middle school complete	1,501	11.0	63	42.0	(32.4-53.4)	
High school complete and above	1,014	7.5	32	31.6	(21.7-44.3)	
Religion						p = 0.236
Hindu	11,751	86.3	546	46.5	(42.7-50.7)	
Others	1,861	13.7	75	40.3	(31.8-50.3)	
Caste/tribe						p = 0.245
Scheduled caste/ Scheduled tribe	5,648	41.5	271	48.0	(42.6-53.9)	
Other backward class	6,206	45.6	283	45.6	(40.5-51.1)	
Others	1,745	12.8	67	38.4	(29.9-48.5)	
Wealth quintile						p = 0.281
Lowest	3,452	25.4	178	51.6	(44.4-59.5)	
Second	1,921	14.1	90	46.9	(37.8-57.3)	
Third	2,672	19.6	119	44.5	(37.0-53.1)	
Fourth	2,727	20.0	120	44.0	(36.6-52.4)	
Highest	2,840	20.9	114	40.1	(33.2-48.0)	
Sex of the newborn						p = 0.343
Male	7,244	53.2	342	47.2	(42.4-52.4)	
Female	6,368	46.8	279	43.8	(38.9-49.1)	
Birth interval for the most recent child						p < 0.0001
<18 months	1,084	8.0	78	72.0	(57.3-89.0)	
18-23 months	1,186	8.7	70	59.0	(46.3-74.0)	
24-35 months	3,234	23.8	141	43.6	(36.8-51.2)	
36-47 months	2,480	18.2	81	32.7	(26.0-40.4)	
48-59 months	1,406	10.3	46	32.7	(24.1-43.4)	
60+ months	1,556	11.4	61	39.2	(30.1-50.1)	
Status of the previous pregnancy outcome						p < 0.0001
Live birth and surviving	9,470	86.5	354	37.4	(33.7-41.4)	
Still birth	317	2.9	21	66.2	(41.5-99.5)	
Live birth but died	1,156	10.6	99	85.6	(70.1-103.3)	
No previous births	2,666	19.6	144	54.0	(45.7-63.3)	
Study area						p = 0.983
Comparison area	5,924	43.5	270	45.6	(40.4-51.2)	
Intervention area	7,688	56.5	351	45.7	(41.1-50.6)	
Total	**13,612**	**100.0**	**621**	**45.6**	**(42.2-49.9)**	

Table 2. Status of mothers' knowledge of complications and care-seeking behaviors and their association with neonatal mortality in rural Uttar Pradesh, India, 2006

Selected characteristics	All Singleton Live Births		Neonatal Mortality			χ^2 p value
	Number	Percent	Number	Rate	(95% CI)	
Mother's knowledge of pregnancy complications[1]						p = 0.083
Poor	6,107	44.9	298	48.8	(43.5-54.5)	
Average	4,184	30.7	194	46.4	(40.2-53.2)	
Better	3,321	24.4	129	38.8	(32.5-46.0)	
Mother's knowledge of newborn complications[2]						p = 0.497
Poor	2,409	17.7	117	48.6	(40.3-57.9)	
Average	6,808	50.0	316	46.4	(41.5-51.7)	
Better	4,395	32.3	188	42.8	(37.0-49.2)	
Mother's knowledge of all complications[3]						p = 0.130
Poor	3,832	28.2	190	49.6	(42.9-56.9)	
Average	7,350	54.0	337	45.9	(41.2-50.9)	
Better	2,430	17.9	94	38.7	(31.4-47.1)	
Pregnancy complications & ANC by a trained provider[4]						p = 0.004
No complication and no ANC	3,833	28.2	145	37.8	(32.0-44.4)	
Complication and no ANC	5,414	39.8	257	47.5	(42.0-53.5)	
No complication and ANC	1,205	8.9	46	38.2	(28.1-50.6)	
Complication and ANC	3,160	23.2	173	54.7	(47.1-63.3)	
Delivery complications & assistance by a trained provider[4]						p < 0.0001
No complications & no assistance	7,350	54.0	281	38.2	(34.0-42.9)	
Complications & no assistance	3,272	24.0	185	56.5	(48.9-65.0)	
No complications & assistance	1,123	8.3	40	35.6	(25.6-48.2)	
Complications & assistance	1,867	13.7	115	61.6	(51.1-73.5)	
TT injection						p = 0.018
None	3,378	24.82	174	51.5	(44.3-59.5)	
One	1,125	8.26	63	56.0	(43.3-71.1)	
Two or more	9,109	66.92	384	42.2	(38.1-46.5)	
Iron folic acid tablet intake						p = 0.437
None	4,985	36.6	242	48.5	(42.7-54.9)	
Inadequate(<100 tablets)	6,515	47.9	289	44.4	(39.5-49.6)	
Adequate (>=100 tablets)	2,112	15.5	90	42.6	(34.4-52.1)	
Total	**13,612**	**100.0**	**621**	**45.6**	**(42.2-49.9)**	

[1] Mother's knowledge about possible pregnancy complications such as severe headache, high fever, edema of the face or hands, unconsciousness, convulsions, vaginal bleeding; delivery complications such as excessive vaginal bleeding, high fever, prolonged labor (>12 hours), convulsions and knowledge about possible postpartum maternal complications such as excessive vaginal bleeding, foul-smelling vaginal discharge, high fever, convulsions, swollen feet/hands, severe headache etc. Based on mean and standard deviation, the score indices for mother's knowledge of maternal complications are 0-3 for Poor, 4-5 for average and 6+ for better knowledge.

[2] Knowledge about newborn complications includes poor feeding or unable to suckle, poor activity/can't be woken up, not crying, excessive crying, cold to the touch, breathing difficulties and chest retraction. Based on mean and standard deviation, the score indices are 0 for poor, 1-2 for average and 3+ for better knowledge.

[3] Mother's knowledge of all complications includes her knowledge of pregnancy complications, delivery complications, postpartum complications and newborn complications as mentioned above. Based on mean and standard deviation, the score indices are 0-4 for poor, 5-8 for average, and 9+ for better knowledge.

[4] Trained provided is a medically qualified doctor, nurse, lady health visitor or auxiliary nurse midwife.

Similarly, NMR was also lower among women who had two or more doses of TT injections than those who had not received any dose of TT injection (42.2 vs. 51.5).

Considering delivery assistance by trained providers with respect to delivery complications, neonatal mortality was lower for those who went for preventive care (“no complication and assistance”) compared to curative care (“complication and assistance”) (35.6 vs. 61.6; $p < 0.0001$).

Table 3. Distribution of essential newborn health practices and care seeking behaviors and their association with neonatal mortality in rural Uttar Pradesh, India, 2006

Selected characteristics	All Singleton Live Births		Neonatal Mortality			χ^2 p value
	Number	Percent	Number	Rate	(95% CI)	
Complete cord care[1]						p = 0.078
No	7,974	70.0	360	45.1	(40.7-50.0)	
Yes	3,458	30.3	131	37.9	(31.8-44.8)	
Complete thermal care[2]						p < 0.0001
No	10,473	76.9	520	49.7	(45.6-54.0)	
Yes	3,139	23.1	101	32.2	(26.3-39.0)	
Breastfeeding initiation						p < 0.0001
Within 1 hour	3,247	23.9	84	25.9	(20.7-31.9)	
2-24 hours	2,528	18.6	70	27.7	(21.6-34.9)	
2-3 days	4,071	29.9	125	30.7	(25.6-36.5)	
>3 days/Not breastfed/ No response	3,766	27.6	342	90.8	(81.8-100.4)	
Breastfeeding initiation within one hour and colostrums						p < 0.0001
No	10,564	77.6	545	51.6	(47.4-56.0)	
Yes	3,048	22.4	76	24.9	(19.7-31.1)	
Newborn complications[3] **and checkup by a trained provider**[4]						p < 0.0001
No complications and no checkup	6,815	50.1	240	35.2	(31.0-39.9)	
Complications and no checkup	5,060	37.2	274	54.2	(48.1-60.7)	
No complications and checkup	902	6.6	28	31.0	(20.7-44.6)	
Complications and checkup	835	6.1	79	94.6	(75.6-116.5)	
Total	**13,612**	**100.0**	**621**	**45.6**	**(42.2-49.9)**	

[1] Umbilical cord cut with boiled blade, tied with sterile thread and nothing applied to the cord stump.

[2] Newborn dried and wrapped immediately after delivery and first bath delayed for 6 hours or more.

[3] New born complications includes fever, breastfeeding problem, breathing trouble, fast breathing, chest-in-drawing, drowsiness, jaundice, diarrhea, persistent vomiting, felt cold, red/discharging eye, skin pustules, umbilical redness or discharge, unconsciousness, and convulsions.

[4] Check up done by a medically qualified doctor, nurse, lady health visitor or auxiliary nurse midwife within one week of birth.

Newborn health care practice, complications and care seeking behaviour and associated neonatal mortality

Table 3 shows newborn health care practice, complications and care seeking behaviour and associated neonatal mortality. NMR was significantly higher in the absence of proper cord, thermal care and delay in breast feeding initiation or providing colostrum (mother’s first breast milk) to new born. NMR was found to be significantly lower among women who practiced complete cord care than who did not (37.9 vs. 45.1; p = 0.078) and also who practiced complete thermal care than who did not (32.2 vs. 49.7; p < 0.0001). Also NMR was found to be significantly lower if the newborn was fed the colostrum within one hour of breastfeeding than who did not (24.9 vs. 51.6, p < 0.0001). Regarding newborn complications and care seeking behaviour, NMR was higher for curative care seeking behaviour ("complication and checkup") than routine care seeking ("no complication and checkup") (94.6 vs. 31.0; p < 0.0001).

Determinants of neonatal mortality

Table 4 shows the effects of mother's knowledge, maternal and newborn health practices and care seeking behaviour on neonatal mortality in four different models. Unadjusted results in Model-1 show significant impact of mother's knowledge of pregnancy and delivery related complications, intake of TT injection, IFA intake, complete cord care, complete thermal care, breastfeeding initiation within one hour with colostrum feeding and mother's education in reducing neonatal mortality. When we adjusted mother's knowledge of complications, mother's health care practices and socio-demographic characteristics in Model-2, mother's knowledge of complications, birth interval and mother's education came out as significant factors for reduction in neonatal mortality. The likelihood of neonatal mortality was 22% lower (OR:0.78; 95% CI:0.60-1.01) among mothers who had better knowledge with reference to those who had poor knowledge of complications. When we adjusted newborn complications, newborn health care practices and background characteristics in Model-3, breastfeeding initiation within one hour with colostrums feeding, complete cord care and thermal care along with birth interval and mother' education came out as significant factors for reduction in neonatal mortality. The likelihood of neonatal mortality among mothers who fed colostrums to their newborn was almost half (OR:0.54; 95% CI:0.41-0.73) with reference to their counterparts.

After we adjusted for all the above factors in Model-4, newborn health care practices such as colostrums feeding, complete cord and thermal care along with birth interval and mother's education emerged as significant factors for reduction in neonatal mortality. TT injection, mother's knowledge of complications was also significant factors for reduction in neonatal mortality. The likelihood of neonatal mortality among mothers who fed colostrums to their newborn remained almost half (OR:0.54; 95%CI:0.40-0.73) with reference to those who did not fed colostrums to their newborn. Also the likelihood of neonatal mortality among newborns who were provide complete cord care (OR:0.84; 95% CI:0.68-1.03) and complete thermal care (OR:0.65; 95% CI:0.50-0.84) were significantly lower than their counterparts.

The likelihood of neonatal mortality among the newborn whose birth interval was less than 18 months was almost twice (OR:1.87; 95% CI:1.33-2.61) with reference to newborns of ideal birth interval of three-four years. However, the likelihood of neonatal mortality among the newborns whose mother were high school and above educated decreased to almost half (OR:0.56; 95% CI:0.37-0.86) with reference to illiterate mothers. Also when the education of mother is low (middle school complete) the reduction in neonatal mortality is less pronounced (OR:0.78; 95% CI:0.58-1.06).

Table 4. Unadjusted and adjusted odds ratios with 95% confidence intervals (OR and 95% CI) showing effects of mother's knowledge, maternal and newborn health practices, care-seeking behaviour and other socio-demographic characteristics on neonatal mortality in rural Uttar Pradesh, India, 2006

Characteristics	Model 1 OR(95% CI)	Model 2 OR(95% CI)	Model 3 OR(95% CI)	Model 4 OR(95% CI)
Mother's knowledge of all complications				
Poor R	1.00[ref]	1.00[ref]	-	1.00[ref]
Average	0.92 (0.77-1.11)	0.93 (0.78-1.12)	-	1.00 (0.81-1.22)
Better	0.77 (0.60-0.99)	0.78 (0.60-1.01)	-	0.77 (0.57-1.04)
Pregnancy complications & ANC status				
No complication & no ANC R	1.00[ref]	1.00[ref]	-	1.00[ref]
Complication & no ANC	1.27 (1.03-1.56)	1.12 (0.90-1.38)	-	1.03 (0.82-1.30)
No complication & ANC	1.01 (0.72-1.42)	1.13 (0.79-1.61)	-	1.16 (0.76-1.73)
Complication & ANC	1.40 (1.18-1.85)	1.45 (1.13-1.87)	-	1.23 (0.92-1.65)
TT injections				
None R	1.00[ref]	1.00[ref]	-	1.00[ref]
One	1.09 (0.81-1.47)	1.05 (0.76-1.43)	-	0.96 (0.67-1.36)
Two or more	0.81 (0.67-0.97)	0.77 (0.61-0.97)	-	0.80 (0.62-1.04)
Iron folic acid tablet intake				
None R	1.00[ref]	1.00[ref]	-	1.00[ref]
Inadequate <100 tablets	0.91 (0.76-1.08)	0.96 (0.78-1.11)	-	0.98 (0.78-1.24)
Adequate >= 100 tablets	0.87 (0.68-1.12)	0.94 (0.71-1.24)	-	1.08 (0.76-1.51)
Delivery complications & assistance				
No complications & no assistance R	1.00[ref]	1.00[ref]	-	1.00[ref]
Complications & no assistance	1.51 (1.25-1.82)	1.41 (1.16-1.72)	-	1.32 (1.08-1.62)
No complications & assistance	0.93 (0.66-1.30)	0.98 (0.69-1.38)	-	0.69 (0.37-1.30)
Complications & assistance	1.65 (1.32-2.06)	1.63 (1.28-2.07)	-	0.96 (0.58-1.58)
Complete cord care				
No R	1.00[ref]	-	1.00[ref]	1.00[ref]
Yes	0.83 (0.68-1.02)	-	0.83 (0.67-1.02)	0.84 (0.68-1.03)
Complete thermal care		-		
No **R**	1.00[ref]	-	1.00[ref]	1.00[ref]
Yes	0.64 (0.51-0.79)		0.64 (0.58-0.83)	0.65 (0.50-0.84)

Characteristics	Model 1 OR(95% CI)	Model 2 OR(95% CI)	Model 3 OR(95% CI)	Model 4 OR(95% CI)
Breastfeeding Initiation with in 1 hour with colostrums				
No ^{R}	1.00[ref]		1.00[ref]	1.00[ref]
Yes	0.47 (0.37-0.60)	-	0.54 (0.41-0.73)	0.54 (0.40-0.73)
Newborn complications & checkup				
No complications & no checkup ^{R}	1.00[ref]	-	1.00[ref]	1.00[ref]
Complications & no checkup	1.57 (1.31-1.87)	-	1.75 (1.44-2.12)	1.65 (1.35-2.01)
No complications & checkup	0.88 (0.59-1.31)	-	0.53 (0.22-1.31)	0.58 (0.23-1.46)
Complications & checkup	2.86 (2.20-3.73)	-	3.82 (2.57-5.67)	3.73 (2.49-5.60)
Birth order				
1st order ^{R}	1.00[ref]	1.00[ref]	1.00[ref]	1.00[ref]
2-3 order	0.69 (0.56-0.85)	0.53 (0.31-0.91)	0.57 (0.29-1.10)	0.58 (0.30-1.11)
4-5 order	0.65 (0.51-0.82)	0.47 (0.27-0.83)	0.58 (0.29-1.15)	0.58 (0.29-1.15)
6+ order	0.88 (0.69-1.12)	0.64 (0.35-1.16)	0.81 (0.40-1.66)	0.79 (0.39-1.62)
Birth interval for the most recent child				
<18 months	2.30 (1.67-3.16)	1.86 (1.33-2.60)	1.88 (1.30-2.70)	1.87 (1.33-2.61)
18-23 months	1.86 (1.34-3.58)	1.80 (1.29-2.52)	1.88 (1.30-2.71)	1.79 (1.28-2.51)
24-35 months	1.35 (1.02-1.78)	1.40 (1.05-1.87)	1.37 (1.00-1.89)	1.41 (1.06-1.89)
36-47 months ^{R}	1.00[ref]	1.00[ref]	1.00[ref]	1.00[ref]
48-59 months	1.00 (0.69-1.45)	1.09 (0.74-1.59)	0.97 (0.63-1.50)	0.98 (0.64-1.52)
60+ months	1.21 (0.86-1.70)	1.29 (0.90-1.85)	1.32 (0.89-1.96)	1.33 (0.90-1.98)
Status of the previous pregnancy outcome				
Live birth and surviving ^{R}	1.00[ref]	1.00[ref]	1.00[ref]	1.00[ref]
Still birth	1.83 (1.16-2.88)	1.25 (0.68-2.29)	1.45 (0.71-2.96)	1.44 (0.71-2.95)
Live birth but died	2.41 (1.91-3.04)	3.04 (1.37-6.75)	3.69 (1.50-9.13)	3.64 (1.48-9.00)
No previous births	1.47 (1.21-1.69)	1.47 (1.21-1.69)	1.47 (1.21-1.69)	1.47 (1.21-1.69)
Interactions variables				
Birth order* Status of the previous outcome	-	0.98 (0.94-1.02)	0.96 (0.91-1.00)	0.98 (0.94-1.03)
Birth interval * Status of the previous outcome	-	0.98 (0.89-1.06)	0.97 (0.87-1.06)	0.97 (0.89-1.09)
Mother's education				
Illiterate ^{R}	1.00[ref]	1.00[ref]	1.00[ref]	1.00[ref]
Literate, < middle school complete	1.02 (0.81-1.29)	0.98 (0.77-1.25)	0.87 (0.65-1.16)	0.93 (0.73-1.19)

Table 4. (Continued)

Characteristics	Model 1 OR(95% CI)	Model 2 OR(95% CI)	Model 3 OR(95% CI)	Model 4 OR(95% CI)
Middle school complete	0.88 (0.67-1.16)	0.83 (0.62-1.12)	0.97 (0.59-1.06)	0.78 (0.58-1.06)
High school complete and above	0.66 (0.46-0.95)	0.61 (0.40-0.94)	0.66 (0.38-0.87)	0.56 (0.37-0.86)
Religion				
Hindu R	1.00[ref]	1.00[ref]	1.00[ref]	1.00[ref]
Others	0.86 (0.67-1.10)	0.84 (0.64-1.09)	0.75 (0.55-1.03)	0.85 (0.65-1.10)
Caste/tribe				
Scheduled caste/ Scheduled tribe R	1.00[ref]	1.00[ref]	1.00[ref]	1.00[ref]
Other backward class	0.95 (0.80-1.12)	1.03 (0.86-1.23)	0.92 (0.75-1.12)	1.01 (0.85-1.22)
Others	0.79 (0.60-1.04)	0.92 (0.64-1.24)	0.89 (0.63-1.27)	0.90 (0.66-1.22)
Wealth quintile				
Lowest R	1.00[ref]	1.00[ref]	1.00[ref]	1.00[ref]
Second	0.90 (0.70-1.17)	0.88 (0.68-1.15)	0.84 (0.63-1.12)	0.88 (0.68-1.15)
Third	0.86 (0.68-1.09)	0.85 (0.67-1.08)	0.76 (0.58-1.00)	0.83 (0.65-1.06)
Fourth	0.85 (0.67-1.07)	0.83 (0.65-1.06)	0.85 (0.65-1.12)	0.84 (0.66-1.08)
Highest	0.77 (0.60-0.98)	0.82 (0.62-1.09)	0.81 (0.59-1.11)	0.80 (0.61-1.07)
Number of live births	**13,612**	**13,596**	**13,596**	**13,596**

Model 1 is unadjusted;

Model 2 Adjusted for mother's knowledge, new born healthy practices, care-seeking and socio-demographic characteristics;

Model 3 Adjusted for newborn healthy practices, care-seeking and socio-demographic characteristics;

Model 4 adjusted for all;

- Not included in the model;

R Reference category.

Other important programmatic factor such as mother's knowledge and TT injection had also shown a positive impact in the reduction of neonatal mortality. The likelihood of neonatal mortality among mothers who had better knowledge was somewhat lower (OR: 0.77; 95% CI:0.57-1.04) with reference to those who had poor knowledge. Almost similar likelihood of neonatal mortality was found among mothers who had two or more doses of TT injections (OR:0.80; 95% CI:0.62-1.04) than who had not any dose of TT injection.

DISCUSSION

Our study looked into the effects of different programmatic factors on neonatal mortality and found that maternal and newborn health care practice such as ANC, TT injection, clean cord care and thermal care, and colostrums feeding and mother's knowledge of complications during pregnancy and postpartum period as significant factors for reducing neonatal mortality. Apart from the health care practices, mother's education and ideal birth interval was also found to be positively associated with neonatal mortality reduction. The results add to the currently limited number of studies conducted in developing countries and provide important inputs for programme. Our study suggests that most of the neonatal deaths in rural India can be preventable if there is proper mother's knowledge of newborn complications, and preventive health care and healthy newborn care practices at the community level.

Though the infant and under five mortality rate in India has declined over the past 2 to 3 decades, the new born mortality rate has declined little over the recent decades and remains 39 per 1000 live births (22). The neonatal mortality rate in the study area was 45.6 per 1000 live births. Improvements in perinatal and newborn health are now seen as crucial to advancing child survival in India. Our study looked into the effects of different programmatic factors on neonatal mortality and found that maternal and newborn health care practice such as ANC, TT injection, complete clean cord and thermal care, and colostrums feeding and mother's knowledge of complications during pregnancy and postpartum period as significant factors for reducing neonatal mortality. Apart from the health care practice, mother's education and ideal birth interval was also found to be positively associated with neonatal mortality. The results add to the currently limited number of studies conducted in developing countries and provide some important inputs for a programmatic setup for reducing neonatal mortality in rural India.

There has been little awareness paid to understanding the causes and determinants of neonatal mortality especially in developing countries like India due to multiplicity of factors. Firstly, in India there are huge number of neonatal deaths and the invisibility of those deaths as deaths take place mostly at home and are generally unattended by health personnel (2, 14, 23). Social invisibility is also linked to an expectation of high mortality. Many traditional societies in India do not name newborns for up to six weeks. Again, much of the factors contributing to neonatal mortality and morbidity have their origin long before a baby is born. Neonatal deaths are often counted within the more popular indices of infant and child mortality, although the factors determining these two mortality indicators are largely diverse [23].

Neonatal deaths is a serious concern both in developing and developed countries, although its magnitude varies significantly between the two, being notably higher among developing countries. A study by Achyut et al. in 1997 (24) shows that neonatal mortality was determined by socio-economic and cultural factors, demographic characteristics of the mother at birth, maternal habitat and environment, medical supervision at delivery and during pregnancy, delivery complications, and child characteristics at birth. Early neonatal mortality rate were higher among older and younger mothers, mothers without tetanus injections, at hospitals, mothers with prior birth complications, and premature infants. Among socio-economic factors, caste and maternal education were significantly related to early neonatal mortality rate. Also a study by Mavalankar et al. in 1991 (25) indicated that the risks of both stillbirth and early neonatal mortality were significantly increased by a history of previous stillbirth, prematurity in the last pregnancy, low maternal weight, clinical anemia, no prenatal care, vaginal bleeding during pregnancy, elevated diastolic blood pressure, convulsions, antepartum hemorrhage, breech delivery, cesarean section delivery, and congenital malformations.

Until recently, the health of newborn babies was virtually absent from policies, programmes, and research in developing world, although four million newborn babies die each year. The time has come that the health interventions for the newborn babies to be integrated into maternal and child health programmes, which in turn need to be strengthened and expanded. Globally some three-quarters of neonatal deaths happen in the first week after birth (25). The newborn period, especially the critical first week of life, has been neglected by both maternal health and child survival programs. As a large country, India presents many problems for both health providers and recipients, which are linked to the capacity of the healthcare system, socio-cultural perceptions of the community and availability of effective interventions to manage the problem. The government looked for ways to add to existing programs and to increase coverage of services, especially given that most neonatal deaths occur in the first few days of life in home settings. Therefore, accessing the impact of maternal and newborn care practices on the neonatal mortality would be important to prioritize interventions to reduce neonatal mortality in a developing country set up. Improvement in neonatal care in India is needed in order to fulfill the National Health Policy to reduce infant and perinatal mortality and to meet the fourth MDG.

Maternal tetanus immunization is viewed as a good indicator of the general health-seeking behavior of a mother. Maternal tetanus immunization during pregnancy is recognized as almost sure protection against tetanus in the mother and the newborn child. Our study also shows that intake of adequate IFA tablets during pregnancy and taking at least two TT injection during the pregnancy greatly reduces neonatal mortality. Public health education programs should be designed to persuade women to be immunized against tetanus. Promotion of such behaviors might be incorporated into health education programs for women who have not been immunized (27). Deliberate programmatic focus is required to ensure expected mothers consume adequate IFA tablets during pregnancy and the care should reach rural poor families as well.

Studies shows that care practices immediately following delivery contribute to newborns' risk of morbidity and mortality (12, 14, 15, 28). These practices include clean cord care (cutting the umbilical cord with a sterilized instrument and tying it with a sterilized thread); thermal care (drying and wrapping the newborn immediately after delivery and delaying the newborn's first bath for at least six hours or several days to reduce hypothermia risk); and initiating breastfeeding within the first hour after birth. In our study, the analysis showed a significant differential in the NMR with newborn cord care and thermal care practices and breastfeeding initiation, which is similar with the finding of the other studies. It is also evident that such practices are very low in a rural set up of a developing country like India. Instead of the proper practices of cord care and thermal care, several and rampant malpractices are in vogue in the society which are quite dangerous for the newborn survival. Cord cutting and tying practices have been identified as risk factors for neonatal infection (28-30) and studies also suggest low coverage of clean cord care practices among home deliveries in South Asia (31).

Certain aspects of reproductive behaviour like early and late child bearing, short birth intervals and higher order births are expected to have a deleterious effect on neonatal mortality (32). Although there had been proliferation of studies to assess the independent impact of each of these variables on children's survival, the relationship is still scarcely understood. Our adjusted result showed that neonatal mortality was almost twice among the newborn whose birth interval was less than 18 months with reference to newborns born with an ideal birth interval of three-four years. Other studies also show that neonatal mortality rates are extremely high for birth intervals of less than 12 months, which is mainly due to premature births (33, 34).

A cost effective continuum-of-care approach can prevent millions of newborn deaths and disabilities. The continuum-of-care approach promotes care for mothers and children from pregnancy to delivery, the immediate post natal period, and childhood, recognizing that safe childbirth in critical to the health of both the women and newborn child (35, 36). Its now time for governments and assistance agencies to take joint responsibility to reduce the needless death of children. Particular attention need to be given to critical childbirth and early neonatal periods-when women and children in developing countries are most likely to die and a vital window of opportunity to save lives exists (2, 7). The health and interests of the mother and child cannot be separated, and the newborn baby, once neglected, is now coming into focus as a part of a broader picture and the link between maternal and child health (14).

Our study suggests that most of the neonatal deaths in rural India can be preventable if there is the proper knowledge of complications and appropriate care seeking behaviours and healthy practices behavior at the community level. Program should focus more vigorously on the spacing methods for optimum birth interval, and colostrum feeding along with improving mother's knowledge of complications and maternal and newborn preventive health care. It is necessary to develop appropriate strategies to ensure that these knowledge, health care and practices reach wider segments of the population. Other studies also showed that improved household practices and use of services, often at the community level, will increase newborn survival (12, 9). Large gains in neonatal survival are linked to other health gains, such as reduced childhood morbidity and disability, prevention of stillbirths, and improved maternal survival, thus contributing also to the achievement of the fourth MDG.

Although our study comes out with interesting finding and adding new dimensions of the neonatal survival with a large representative sample size, possible limitations are inherent to a cross-sectional survey of this type that involves reporting of past behaviors. For example, the primary outcome (death) was known by respondents prior to the measurement of the exposure (knowledge and care practices), and this knowledge may have biased the recall of behaviour or events occurring prior to death. The study was conducted among a largely illiterate population, and this may have hindered the respondents' ability to report some types of information accurately (21). However, a two-year recall period was chosen to minimize recall bias, while allowing for sufficient sample size. Rigorous methods were employed to maintain data quality. Many other characteristics such as birth weight and preterm births which were not measured in the survey might have confounded this association.

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Chapter 4

UNILATERAL VERSUS SEQUENTIAL COCHLEAR IMPLANTS IN CHILDREN

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In pediatrics, there has been much research thus far investigating the role of unilateral versus sequential cochlear implants. It is clear that cochlear implants can provide hearing to a profoundly deaf individual. For children with hearing disabilities, a common question posed to pediatricians is: "My child had one cochlear implant as an infant, and now as an adolescent, will another one help?" Many children who undergo a successful unilateral cochlear implantation may still have difficulty clearly listening in noisy environments, limiting the chances for "incidental learning" in day-to-day life with just the one implant. This is just one example of a potential advantage of sequential cochlear implants. This study addresses that very issue by analyzing the role of a second cochlear implant at various points in the future.

INTRODUCTION

There is a significant amount of literature in the field of pediatrics concerning the role of cochlear implants in the setting of severe-profound hearing disability. Cochlear implants can be unilateral, sequential (separated by a number of months or years), or rarely bilateral based on clinical circumstance (1).

The basic principle behind the implant, as described by the US National Institute on Deafness and Other Communication Disorders is as follows: A cochlear implant is a small, complex electronic device that can help to provide a sense of sound to a person who is profoundly deaf or severely hard-of-hearing. An implant does not restore normal hearing.

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Instead, it can give a deaf person a useful representation of sounds in the environment and help him or her to understand speech. A cochlear implant is very different from a hearing aid. Hearing aids amplify sounds so they may be detected by damaged ears. Cochlear implants bypass damaged portions of the ear and directly stimulate the auditory nerve. Signals generated by the implant are sent by way of the auditory nerve to the brain, which recognizes the signals as sound. Hearing through a cochlear implant is different from normal hearing and takes time to learn or relearn. However, it allows many people to recognize warning signals, understand other sounds in the environment, and enjoy a conversation in person or by telephone.

LITERATURE SEARCH

A PubMed literature search was conducted. The bibliographies of retrieved references were reviewed for additional publications. Inclusion criteria included: English language, publication date of year 2000 onwards, and must have been peer-reviewed. Exclusion criteria included: foreign language, non-peer-reviewed articles, publication date prior to year 2000 and primary patient population ≥18 years of age. Outcome measures varied among studies, and included listening performance and speech perception, and vocabulary orlanguage tests. Aggregate statistical analyses used in the studies included paired T tests and ANOVA. Values were considered to be statistically significant if the p value was <0.05.

FINDINGS

The key findings of recent studies are summarized in Table 1. Each result noted is supported by multiple other studies, but these exemplify the major current issues.

Sharma et al. (2) studied cortical auditory evoked potentials in early and late implanted children. Early implanted children received cochlear implants prior to 3.5 years of age, while late implanted implied after seven years of age. Results showed rapid cortical development in the early group, and aberrant development in the late group. Additionally, “CAEP morphology and cortical response latency” was different for early and late implanted children. This study was vital in delineating the “early sensitive period,” a period of time in a child’s auditory development that was most receptive to cochlear implants. It is the first of the studies in this group to support early age of implantation to minimize the duration of deafness prior to initial implantation.

Papsin et al. (3) and Geers (4, 5) also encourage early age of implantation, but add other interesting results. The Papsin et al. (3) review noted that short inter-stage interval (time between implantation of first and second ears) was important for development of binaural processing. Geers et al. (4, 5) found that children with profound hearing loss have higher nonverbal IQs than verbal IQs, and also that higher nonverbal IQ is an independent factor for improved language outcomes. Geers et al. (5) re-emphasized importance of early age of implantation and the negligible advantage of a second implant with respect to language testing. Language scores were significantly correlated with age of first cochlear implant, not with receipt of the second sequentially-acquired implant.

Table 1. Summary of key findings of recent studies

Study	Year	Population	*n*	Outcome measures	Results
Sharma	2004	Unilateral CI	21	CAEP	• Presence of early sensitive period for auditory development (<3.5 years of age)
Papsin	2008	Unilateral vs. Sequential CI	N/A	Aggregate behavioral and electrophysiological measures	• Supports early AOI and short inter-stage interval.
Geers	2011	Unilateral CI	112	Verbal reasoning and language tests	• Supports earliest AOI as possible • Cognition is a significant factor in later language outcomes
Geers	2012	Unilateral vs. Sequential CI	60	Vocabulary and language tests	• Earlier AOI = independent predictor of improved spoken language outcomes • 2^{nd} implant and longer duration of CI use do not provide significant added benefit
Kim	2013	Unilateral vs. sequential CI	42	Speech perception tests in quiet and noise; functional benefit tests	• Improved benefit in noisy situations and daily life with bilateral CI. Despite long inter-stage interval between CI, significant improvement was seen.

AOI = age of implantation; CI = cochlear implant; CAEP = cortical auditory evoked potential.

Kim et al. (1) reported that speech perception abilities in quiet environments improved quickly for those with sequential implants (within 1 year of second implant), but then did not differ from those with unilateral implants only (“monosyllabic word test, phoneme: p = 0.052; word: p = 0.125) and common phrases sentence test (p = 0.062) 6 month after the second implantation, and the Categories of Auditory Performance score (p = 1.000, 1 year after the second implantation). Functional hearing in noisy environments was improved with sequential implants compared to unilateral implants (p = 0.018). And finally, no significant influence of long inter-stage interval (>5 years) was noted (in quiet or noisy environments).

DISCUSSION

The studies reviewed represent the major findings over the past decade in the research on cochlear implantation in children. Findings of these studies are similar to other previous studies. The major factors identified affecting the long term benefit of cochlear implants in children appear to be the following: age of initial implantation (implying total duration of deafness prior to implantation), inter-stage interval, and age of second implant. Most studies agree that the earlier the initial implant is, the more benefit to language development will be gained. Earlier research suggested that a short inter-stage interval was vital for improved language development, and more recent evidence suggests that a long inter-stage interval is acceptable as long as the child responded well to the first implant. Age at second implant is an area of controversy, partly due to the discordant research concerning the inter-stage interval.

Finally, there is the issue of simultaneous bilateral cochlear implantation. While it has not traditionally been a recommended option, due to the emerging body of evidence suggesting added benefit of a second implant, it is becoming a more attractive option. Peters et al. (6) found that bilateral implantation has increased due to findings of improved speech perception and utility of binaural hearing. Geers et al. (5) succinctly described the state of the evidence thus far concerning bilateral implantation: "while there are many reasons to believe that simultaneous implantation, early in the preschool years, would provide the best chance of a bilateral advantage for spoken language outcomes, there are currently no conclusive data to support this expectation" (5).

Most studies reviewed have epidemiologic and methodological limitations. Geers identified some inherent biases within the population groups being studied: 1) socioeconomic status (SES) – "children from higher SES families are more likely to receive cochlear implants at younger ages, further enhancing their language outcomes" and 2) a deaf child's nonverbal IQ – higher nonverbal IQ is a strong predictor of language progress (5). These are population characteristics that affect each child's ability to receive an implant and their inherent ability to gain benefit from it, both of which impact the final outcomes of studies. Additionally, Geers et al. (5) utilized primary outcome measures of vocabulary tests and language assessments. These did not take into account such things as noisy environments; yet, improved hearing in these environments was precisely the advantage of sequential CI as identified by Kim et al. (1). The heterogeneity in outcome measures should lead one to interpret aggregate analyses such as this literature review with caution.

CONCLUSION

The evidence at hand converges on one common point: cochlear implants offer substantial benefits in terms of hearing to the profoundly deaf population. Taking this one step further, much of the evidence agrees that the earlier the first implant is placed, the more potential there is for further language development. Other studies focus more on the time between sequential cochlear implants. Historically, it has been believed that less time between implants is more beneficial; however, new evidence shows that if the child responded well to the first implant, an extended inter-stage time period may be acceptable and may still confer significant advantages (1). The evidence may appear to be heterogeneous, but in fact is simply evolving. It is likely, given the evidence, that the benefit of cochlear implants is asymptotic, with the most benefit gained if implanted early, and less (but still significant) benefit if implanted later.

Studies have suggested that further research should be conducted to identify the point at which a second cochlear implant provides so little benefit that is not cost-effective. These studies were conducted prior to 2013, when new research in both quiet and noisy environments has now suggested an added benefit of a second implant not previously identified on vocabulary and language testing.

Based on the review, following general conclusions can be inferred: 1) early age of implantation is essential to give the child the best possible outcome; 2) if the child did not respond well to the first implant, a second implant within six months – one year may be beneficial; 3) if the child responded well to the first implant, a second implant can be considered later, even in adolescence, to assist with better hearing and secondary learning in noisy environments (1-8).

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Chapter 5

MENTAL HEALTH SERVICES FOR FOSTER CHILDREN

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Children within the social service system, particularly foster care, are in need of comprehensive mental health services. Research has found that foster care children can primarily be diagnosed with one of four primary diagnoses that correspond to specific ages-related differences: adjustment disorders (28.6%), conduct disorders (20.5%), anxiety disorders (13.8%) and emotional disorders (11.9%). Thus as the numbers of children entering the system continues to escalate, the demand for mental health services also rises. Simultaneously, as the demand increases so have the barriers for foster children in accessing mental health services. Many of these barriers are system barriers that continue to keep utilization rates of foster children receiving services low. In a rural county with low penetration rates, a pilot project involving the Department of Human Services (child welfare agency), the Department of Mental Health, and the Department of Social Work was developed to increase the penetration rates for providing mental health services to foster children by overcoming the barriers to services. A number of barriers were identified, including system barriers because of the silos between the agencies. The project demonstrated the role of the University in facilitating a change process when collaborating with two different county agencies. It also showed the need for cross training staff. Residual benefits include increased trust, better understanding of the various jobs and roles of workers, and better communication between staff of the two county agencies.

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INTRODUCTION

A child's development is dependent upon the relationship between the child and the care giver. Within the first six months of life, the child develops a number of behaviors to attract a care giver and to discriminate between care givers (1). This leads to developing attachments with specific caregivers in order to ensure proper development. Bowlby (2) refers to attachment as the strong propensity for the young child to seek proximity to and contact with a specific figure in certain situations particularly when frightened, tired, or ill. This contributes to a disposition to behave in a way that is an attribute of the child's behavior that only changes slowly over time. Within the first year of life, a child develops four main patterns of attachment relationships; secure, insecure avoidant, insecure ambivalent/resistant, and disorganized (1). Through this attachment with the caregivers, the child learns a variety of coping behaviors on how to deal with various aspects of life. These attachments are not innate but need to be developed over time. The way the child develops these attachments is through continual contact with the caregiver. Zlotnick, Tam, and Soman (3) showed that adults who had been in foster care as children without addressing the health or mental health needs were more likely to have health and mental health problems than other adults.

When problems occur in the family structure that may cause disruptions with the contact between the child and the care giver causing the child to begin to regress in his/her development and even not developmentally progress as desired. In some of these cases, CPS (Child Protective Services) intervenes and moves the child into a more supportive environment. However, there is no telling what the effect that this move has had on the child and the development of the child. On the one hand, it is perceived that a more stable environment should be helpful in that the child would be able to reestablish positive attachments with care givers to continue his/her growth development. On the other hand, there may be some role confusion because the child had previously developed attachments with former caregivers and there is questioning as to the role of the new caregiver and some difficulty in extinguishing previous attachments to move forward in establishing new ones.

The assumption is that by placing a child in either a relative or non-relative home that appears to be stable, the child will be able to develop attachments and continue the development process. However, Burns, et al. (4, 5) have identified that there are a number of behaviors that emerge as a result of the move and that these should be addressed through some type of mental health services being provided. Burns et al. (5) identified that almost half of the children who were removed by CPS and were in placement demonstrated some mental health need and that those in non-relative placement demonstrated those behaviors between 30 to 50% more than those in relative placement.

The provision of mental health services to children in placement, or foster care, is complicated since it bridges two different service delivery systems. On the one hand there is the child protective system, CPS, which is mandated to protect the child, including possible removal from the parental home and placement in a foster home, either relative or non-relative. Second is the mental health system, which is charged to provide mental health services for those individuals (both adults and children) who receive public benefits, such as Medicaid. This becomes more complicated since as demand for CPS services has increased, so have the barriers in the provision of mental health services (6). This also is complicated by the definitions used by each of the systems in how they provide those services. For example, CPS is required to respond to a situation within a certain timeframe depending on the severity of the report. However, mental health does not have the same time constraints in how they provide services unless it is a life and death situation or the person is a danger to self or others.

The question and purpose of this pilot project was to identify the barriers that exist between the two services and then to identify ways to overcome those barriers to improve the mental health delivery system to children in the foster care system.

LITERATURE REVIEW

In a study comparing children in the foster care system with children receiving Supplemental Security Income (SSI), dosReis et al. (7) identified that those in the foster care system were more likely to have a mental disorder (57%) than children receiving SSI (26%) or fifteen times greater than children receiving any type of aid (4%). Similarly, Farmer et al. (8) identified that children in either foster care or with contact with social services were more likely to receive mental health services than children living in poverty. In addition, Farmer et al. (8) identified that many of the children in foster care continue exhibiting mental health behaviors into their adult lives. Halfon, Berkowitz and Klee (9) identified that foster children can primarily be diagnosed with one of four primary diagnoses corresponding to specific age-related differences: adjustment disorders (28.6%); conduct disorders (20.5%); anxiety disorders (13.8%); and emotional disorders (11.9%).

As the numbers of children entering the system continues to escalate, then the demand for mental health services should also continue to rise. However, the current economic conditions have seen dramatic reduction in the provision of mental health services. With a growing demand and the reduction in service delivery, there has been an increase in the barriers for children and especially foster children to access mental health services (6). The question is what is the nature of these barriers and can they be addressed to streamline the provision of Many of these barriers are system barriers that continue to keep utilization rates of foster children receiving services low. This pilot project was developed to identify the barriers in the provision of mental health services to foster children and to identify some strategies to improve the service delivery of mental health services to foster children in Kern County, California.

KERN COUNTY

Kern County is a rural county and the county seat is Bakersfield. California has a county system of governance and the provision of services. A county system means that each county has a separate, self-governed delivery system that is supported primarily by county funds. Although the state does track county services to see how each county ranks in the delivery, the operations and coordination of services relies on each county.

Within Kern County, the utilization rate, or the rate that children in the foster care system were receiving mental health services prior to the pilot project was under 30%. There had been a county developed committee established to try to improve the utilization rates, but the rates remained consistent for about ten years. Up until 2001, there was no social work program in the County but in 2001, a social work program was begun at California State University, Bakersfield. The program was receiving Title IV-E funding to improve the child welfare workforce in the County.

Kern County also has a high percentage of Hispanic families representing about 46% of the County's population. A percentage of these families are undocumented as a result of employment opportunities in agri-business. In addition, many of these families speak Spanish in the home, thus making language a potential barrier to service delivery.

The question continued to remain of how to improve the mental health delivery of services for children in the child welfare system and particularly in the foster care system. Could the social work program play a role in the development or improvement of the delivery of mental health services?

OUR STUDY

The social work program faculty met with the child welfare service administrator and the director of children's mental health services to begin discussing the creation of a pilot project that would improve the delivery of mental health services to foster children by reducing barriers and by using students from the social work program to assist in the delivery of services in May 2010. At that time, it was identified that there had been a committee in existence for about ten years but the utilization rates had not improved. In addition, both county agencies were experiencing cuts in staff due to the California budget crisis and the potential of creating a pilot project where students would be involved in the delivery of services seemed very attractive. It was also identified that whereas the overall county utilization rate was under 30%, the provision of mental health services for foster children between the ages of 0 to 5 was negligible. Thus, the project initially targeted the provision of mental health services to the 0 to 5 age foster child.

In addition, it was identified that there were a number of barriers that existed between the two systems that may be preventing the timely provision of mental health services. Some of these barriers included the differences in mandated charges between the two agencies. For example, the Department of Human Services, the department charged with the provision of child protective services, has a mandate to investigate a claim either within 24 hours, if the case is deemed an emergency, or within a week. However, the Department of Mental Health did not have the same time mandate and much of the time that it took for a child to be evaluated and seen by a therapist was dependent upon the waiting list. In addition, there was no mandate for a child within the child protective system to even be seen by a mental health professional and that sometimes the behaviors appeared after months of being in placement necessitating an actual court order for the child to have a mental health assessment, since once the child is in foster care, he/she is under conservatorship care of the State needing a court order for any treatment provisions. The need for obtaining a court order for an assessment could take a while and might also raise a perceived level of competence about the foster parent, which in reality would not be the situation at all. Thus, there were a lot of foster children who were just 'falling through the cracks.'

With the faculty from the department of social work collaborating with both the administrators and staff from the two county agencies, the pilot project was launched with the first cohort consisting of four students, three of whom were IV-E stipend recipients and also employees at the Department of Human Services and one traditional student receiving a stipend from mental health. It was also identified that some of the students should be Spanish speaking to address the high percentage of Spanish speaking families in the County. The first meeting of all partners of the project was to be in August 2010, immediately prior to the beginning of the 2010-11 academic year. The meeting was designed as an orientation for the students and to begin establishing the ground rules as to how the project would be implemented. In addition, since the Department of Mental Health did not have an MSW to provide the supervision for the team of students, a faculty member from the Department of Social Work acted as the field instructor along with the Department of Mental Health staff member who had a Masters in Marriage and Family Therapy as the task supervisor.

FINDINGS

Initially, the going was a little slow identifying a number of barriers. The first was the issue of access to all the new children into the system. To address that issue, a request was made to county counsel to request a standing order that all new children into the foster care system will be screened within 60 days. This order was passed, but then there was the issue of how to identify who those children were? The Department of Human Services has an emergency placement facility, Jamison Center, where all children first come to that center prior to being placed into foster care, except for many of the 0 to 5 year olds who go directly into an emergency foster home. Sometimes it would take a number of days for the children coming into Jamison Center to enter into the computer database. However, one of the students identified that Jamison Center kept a hand written log of each child entering the Center. By accessing the log, it was possible to be able to begin the assessment process early enough for the child to be assessed. There was still the question of accessing those children who went directly into an emergency foster home without first stopping at Jamison.

In addition, it was quickly realized that the 60-day mandate for assessment was not long enough. It was identified that the County Regional Center (for children with developmental disabilities) had 120-day assessment process and there was a request back to the county counsel to see whether the order could be amended to the 120-day initial assessment to conform with the Regional Center order to assess for disabilities. This process took longer than anticipated, but was finally accomplished about eighteen months after it was initiated.

Another barrier identified was the electronic databases that were used by each of the two county agencies. The child welfare agency maintained all their records on the CWS-CMS record keeping system; whereas, the mental health agency kept their records on the Anasazi record keeping system. The two are not compatible for interchange and it was quickly identified that there would need to be some cross training on how to work the two systems. This led to initially creating teams of students where one student would learn the mental health system while the other would be fluent in the child welfare system. This way, as a team, then each child would be able to be entered into both systems and there would be joint communications.

This created another barrier in that it necessitated that two students had to work on every case, thus limiting the number of cases that could be seen. As a result, this was changed the second year of the pilot student where each student was cross trained on both systems. However, the other barrier of confidentiality of the information being entered, especially entering mental health data into the child welfare system may violate HIPPA guidelines. Thus, key terms were identified to let the child welfare workers know that the child had been screened by mental health without violating any confidential medical information and thus being in compliance with HIPPA.

A third barrier arose around the misperceptions of the workers in each respective agency about the workers of the other agency. In other words, there was a lack of trust between the workers toward the other agency. By having workers cross-trained and working within the other agency, it became evident that trust began to build. This led to the students making presentations to each agency staff and enhancing greater agency cooperation.

As a result of the students providing the services and being cross-trained on both systems, there was approximately a doubling of the county utilization rate for foster children (increase to 53% from less than 30%). In addition, with the initial target being 0 to 5 year olds, it was identified that the older siblings of the population were also being screened, thus increasing the numbers and helping increase the overall utilization rate just by adding the siblings of the 0 to 5 age children. A problem arose at the end of the academic year and the question of how the project will sustain itself while there are no students in the project during the summer months. There was some discussion about seeing if the next batch of students could start sooner to address this gap in services; however, it was resolved that the Department of Mental Health would hire some temporary help in order to sustain the program during the summer.

Because of the success of the first year of the pilot, there were six students who wanted to participate the second year of the project. Four of the students were IV-E recipients and current employees of the Department of Human Services and two of the students were receiving a California mental health stipend that was structured similarly to the IV-E stipend. As previously mentioned each student was cross-trained and rather than working in teams, were able to work more independently. This led to a more efficient way of operating the project. It was also determined to provide services to all foster children and not only the 0 to 5 year old children. Thus, any child newly entered into the foster care program would be eligible for the standing initial screening process just to begin access to the mental health system.

During the second year of the project, the State began addressing a court order for every county child welfare agency to work more closely with county mental health agency. This was classified as the Katie A decision, and there was some concern about how counties would address this issue. The mandates are currently being worked out through a state mandated core practice model plan that was presented in March 2013. However, as a result of this pilot project, it initially appears that the relationship between the child welfare agency and the mental health agency provide a good foundation for the County to be in compliance with the Court order.

As the project entered its third year there are some concerns. Whereas the first two years of the project recruited the majority of the students from students who were receiving IV-E stipends and those individuals were employees of the child welfare agency returning to school to earn their MSW, the third year did not have any of the Department of Human Service employees receiving IV-E in the class. Thus, the project moved from six students participating in the project to three this third year. None of the three were child welfare employees. What we learned was that this created some access concerns on reaching the new foster child population. To address this, the child welfare agency assigned a liaison to the project that was to assist and to work as a team member with the project to facilitate access. What was realized is the value of having an employee of the child welfare agency as a team member to facilitate access. It also brought to awareness another barrier in the assignment of students by the child welfare agency to this project. Since the previous Title IV-E students had also been employees and were juggling their employment responsibilities with their student intern responsibilities, they were not on the job for about 40% of the time while completing their internship hours. To address this, the child welfare agency used a provision in the placement guidelines that stated that if a student was assigned to a new job, then the new placement could be considered as the internship. Since the pilot project was within the administrative division of the child welfare agency, then none of the new positions fit within the criteria for a placement. This is being explored by seeing if the project can be placed within one of the standing divisions within the child welfare agency, such as family services, in order to make it feasible for employed students to have this placement experience as part of their internship degree requirements.

DISCUSSION

This pilot project is demonstrating that a social work program in a county can have an effect on improving service utilization rates. In addition, during difficult times when agencies are being forced to reduce budgets, which usually translate into staff reductions, a social work program can be very influential in providing new and enhanced services.

The pilot project also showed that a social work program can take a leadership role within the community to identify barriers to services and developing strategies that improve the service delivery system. Thus, the program is not only educating students to enter the workforce, but the social work program is able to work with county agencies to problem solve and identify new techniques and mechanisms to meet county needs.

Another finding was that the role of IV-E students in participating in the project was very beneficial on a number of counts. First, it helped provide a deeper understanding by child welfare workers of the role of mental health and understanding some of the language differences. In addition, it is providing the ability for child welfare staff to be cross-trained on the mental health data management system and vice versa for the mental health staff with the child welfare data management system. This helps with improved communications between the two agencies and better cooperative relationships.

By the social work program working with the two county agencies, it was possible to address and identify barriers and begin to work on addressing them without prejudice or concern about implications on either agency. There is no competition for resources by the social work program at the university with either county agency, thus, making the relationship more equal. The downside is that the social work program, as an educational entity, does not have the status with county government. Thus, when it was identified that the 60 day assessment was too short and needed to be doubled, it was dependent upon the county agencies to have that agreement signed by county counsel while the social work program had to sit on the sidelines and wait for change to take place. In addition, every year the academic year comes to a close, there is the question of how to sustain the project over the summer months when there are no students conducting their internships.

With the state initiation of the Katie A core practice model, the project demonstrated that by having both child welfare and mental health staff working together, that services can be improved. It also demonstrated a better understanding of the differences and similarities in how both agencies operate. Child welfare staff became more aware of HIPPA regulations that govern the confidentiality requirements of mental health staff while mental health staff became aware of the time constraints the law places on child welfare workers for investigating a claim. The project brought a better understanding of the nature of the work between the two agencies and is part of the outcome expected by the Katie A core practice model.

There continues to be new challenges that are being confronted as the project proceeds as mentioned above with the identification of student interns. However, now there is a better communication system between the two agencies and the ability to cooperative work through these issues is enhanced.

Implications for Practice

The pilot project between the social work program and county agencies was a win-win-win scenario. It helped the county address a specific need to address and thus improve the delivery of services to foster children in the county. Second, it helped to build a sense of cooperation between the county agencies and the university. Third, it provided opportunities for the staff of both agencies to gain a better understanding of the operations of each other improving attitudes and understanding about how the other respectively operates. There was a residual effect of this in that the county is in compliance with a court order for the two agencies to work collaboratively. Fourth, it provided a unique opportunity for the social work program to become involved with direct delivery of services, thus creating opportunities for faculty to address and understand delivery of services within the county dispelling the notion that the university is an ivory tower. And finally, it provided a unique opportunity for the students to be engaged in state of the art services and enhance their skill level for greater performance and marketability. Thus, the role of social work programs to become engaged in community problem solving issues is important, not only for the field and the profession, but also for the learning environment.

Next Steps

The project will continue and there continues to be new challenges to address. As mentioned, the State introduced the Katie A Core Practice Model in March and the implications of these practices on service delivery by the two agencies are being identified. However, the social work program is involved and is able to look at these issues objectively and assist the implementation of the core practice guidelines.

Second, there continues to be the issue of student internships, how many, and the mix from child welfare and mental health. This is compounded by how to interest student employees when the agency policy makes it difficult to do so. These are continuing discussions that will be addressed in the future.

CONCLUSION

As resources become tighter and the provision of services becomes more challenged, it is important for agencies to be able to work more collaboratively to address community problems. The issue of providing mental health services to foster children continues to be a growing problem with the number of age related disorders continuing to increase and the ability to treat them diminishing due to reduced resources. In addition, there is the growing problem of drift between the various foster services that tend to contribute to increased problems within the foster care population (10). These all lead to new ways of providing services and the role that the university can play in being the link to more improved service delivery. Too often there seems to be a disconnect between what is being taught in the classroom and what is actually happening in practice and by the engagement of the social work program in the development of pilot projects, like the one mentioned above, then it is possible for university faculty to begin to understand and address community issues while helping students learn the most current techniques to address those problems. This is a model that is a winner for all participants.

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Chapter 6

GENDER DIFFERENCES IN CHRONIC MALNUTRITION OF CHILDREN

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Anecdotal evidence and welfare input indicators such as care of illness and food intake level suggest that daughters seem to be more disadvantaged in the intra-household allocation of resources. However, when it comes to output indicators of well-being, males are paradoxically more often stunted than females. This chapter re-investigates gender dimorphism in up to 110 nations by conducting a meta-analysis of stunting rates using data from the WHO Global Database of Child Growth and Malnutrition with a reference year of 2000. Descriptive analysis demonstrated that stunting was higher among males (27%) compared to females (25%), and a clear majority of studies (83 nations) found that girls had a better net-nutritional status compared to their male peers (24 studies), even though three studies found no bias against either. Regression analysis was conducted to identify which factors might have impacted dimorphism around the globe. By controlling for a number of geographic, economic, and political variables as well as nutritional and health factors, this research found that increasing daily calorie supply was disproportionably beneficial for daughters. This is probably the result of parents prioritizing sons in the intra-household allocation of resources when the food supply is scarce. This research also suggests that the female chromosomal advantage to overcome nutritional stress might explain the paradoxical finding that girls fare better when it comes to stunting. The paper concludes that sexual dimorphism is much more important than gender dimorphism around the globe, casting doubt on the usefulness of anthropometric indicators of gender discrimination in society.

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INTRODUCTION

It is commonly accepted that females face strong discrimination in society. In fact, gender discrimination is culturally rooted and dates back hundreds of years. Anecdotal evidence comes from numerous proverbs that can be found in various cultures and societies around the globe:

> A Hindu proverb (1): “They who are full of sin beget only daughters.”
>
> An English proverb (2): “Two daughters and a back door are three errant thieves.”
>
> A Japanese proverb (3): “Having three daughters is a sure way to stay poor.”

In a society where women are traditionally of less social value, parents treat sons better than daughters, as the former is a better economic investment into the household’s future. Not surprisingly, several comparative studies have reported intra-household allocation biases with regard to vital resources such as foodstuff and medicine (4, 5). In a worldwide meta-analysis, boys were found to be more often sent to doctors and hospitals than their female peers: in 26 studies, sons were more often treated during illness compared to only 14 surveys where daughters more frequently received medical care (see Table 1). In a similar vein, boys more often received food from their parents than girls: in five studies, preferential treatment of foodstuff was given to sons, whereas in only two surveys, daughters were more often fed.

Food intake and care of illness ratios (see Table 1) are both common input indicators of human welfare, generally understood as proxies for gross nutritional or gross health status. Another common way to assess gender bias regarding the intra-household allocation of resources by parents is by examining output indicators of human well-being, notably net nutritional or net health indicators such as height (and sometimes weight). This is because children become stunted in stature if they consume a lesser quantity and quality of food, and outbreak of disease leads to human growth retardation as energy input is first allocated to the immune system. At the same time, many diseases such as tuberculosis are nutritionally related, implying that patients would have not been infected if they had been consuming a proper diet. In a meta-analysis on stunting according to gender, previous research found that actually more boys than girls were stunted (see Table 1). This paradoxically means that parents might have preferred daughters (35 studies) as opposed to sons (six studies) regarding the intra-household allocation of medical and nutritional resources. This is a disturbing finding that fundamentally contradicts the anecdotal evidence indicated in the proverbs mentioned above. More importantly, it also opposes evidence from input indicators based on food intake and care of illness (Table 1), both of which demonstrate a bias in favor of sons.

In this paper, worldwide gender disparities are reassessed by conducting another meta-analysis of gender-specific stunting rates. Therefore, this paper introduces a new, more comprehensive and global data source for this purpose. The descriptive analysis of the new data pays special attention to the identification of regional patterns in gender discrimination. Second, statistical regression analysis is conducted to identify which factors might have impacted male versus female stunting ratios around the globe. Lastly, some logical explanations are given for the paradoxical finding that sons were more often stunted than daughters, even though men seem to be historically privileged and receive more food and medical provisions within the household.

Table 1. A meta-analysis on dimorphism by number of studies

Male-to-female child indicator	Food intake			Care of illness			Stunting (Meta Analysis A)			Stunting (Meta Analysis B)		
Bias in favor of:	Boys	Girls	Neither	Boys	Girls	Neither	Boys	Girls	Neither	Boys	Girls	Neither
Region:												
Asia	5	1	5	6	2	0	1	3	0	14	24	1
Africa	0	1	0	16	9	3	5	22	0	5	41	0
Latin America	0	0	3	4	3	0	0	10	0	4	12	1
ALL (incl. other)	5	2	8	26	14	3	6	35	0	24	83	3
Source:	DeRose et al. (4): Table 3			United Nations (5): Table 11			United Nations (5): Table 51.*			This study		

Notes: * Stunting for children under 3 years of age. Latin America including the Caribbean.

OUR STUDY

Since the 1970s, child undernutrition has been commonly measured by three indicators: height-for-age, weight-for-age, and weight-for-height (6). This research focuses on height-for-age as an indicator of undernutrition among pre-school children. Unlike weight-for-age or weight-for-height indicators, which are sensitive to environmental changes in the short run, height is an indicator of chronic malnutrition and overall underlying living conditions (6) since growth deficits in height accumulate over longer periods of time. In other words, height a better overall standard of living indicator than weight as diarrheal outbreaks and macroeconomic shocks such as famines or natural disasters largely affect weight-related indicators in the short run. As this chapter focuses on a cross-section analysis (see below), it was impossible control for these dynamic factors in a global comparison, leaving height-for-age the more robust and reliable indicator. Further, this research investigated gender differences in undernutrition of children, as parents might treat their daughters or sons differently in extreme situations such as famine. For instance, daughters were found to be at more of a disadvantage in food consumption during Mao's great famine (7), whereas they were somewhat advantaged during Kim Jong Il's great famine (8). Interestingly, both famines occurred in traditional Confucian societies of East Asia, which place high emphasis on sons, and both nations were socialist ones when the famine occurred. Put simply, it is obvious that during calamities, parents might react differently when it comes to the allocation of intra-household resources such as food and medicine, both of which might result in gender-specific growth retardation of their offspring.

Data on height-per-age were taken from the WHO Global Database on Child Growth and Malnutrition, and a discussion on this source will follow in the next section. In general, growth retardation among pre-school girls and boys is referred to as 'chronic undernutrition' or 'stunting,' with rates calculated as follows:

$$\text{Percentage of pre-school girls that are stunted} = \frac{\text{Number of pre-school girls that fall below minus two standard deviations from the median height-for-age of girls of the NCHS/WHO standard}}{\text{Total number of pre-school girls that were measured}} *100$$

$$\text{Percentage of pre-school boys that are stunted} = \frac{\text{Number of pre-school boys that fall below minus two standard deviations from the median height-for-age of boys of the NCHS/WHO standard}}{\text{Total number of pre-school boys that were measured}} *100$$

Note that a discussion on the NCHS/WHO standard will follow in a later section of this paper. To assess gender disparities in height, this research uses the ratio of stunting by gender multiplied by 100, which will henceforward be referred to as the ‘dimorphism ratio.’ The dimorphism ratio is thus defined as:

$$\text{Dimorphism ratio} = \frac{\text{Percentage of pre-school boys that are stunted}}{\text{Percentage of pre-school girls that are stunted}} *100$$

It follows that if the dimorphism ratio exceeds 100, then boys have a higher ratio of stunting compared to girls, meaning that females suffer less often from undernutrition than boys based on their height-for-age score. This tentatively indicates that parents seem to prefer daughters over sons with regard to the intra-household allocation of foodstuff and medical provisions (4, 5). Consequently, if the dimorphism ratio falls below 100, then girls have a higher ratio of stunting than boys, which somewhat suggests that parents have preference for sons regarding the intra-household allocation of resources. Lastly, if the ratio is about 100, this roughly indicates no bias against either gender.

Comparing the stunting ratios among boys and girls is a common way to investigate gender disparities, especially in East Asia where there is strong Confucian son-preference (5, 9). As a disadvantage, it should be noted that the indicator does not account for the number of siblings or the birth order among offspring (10), both of which likely affect the intra-household allocation of resources among parents. The second disadvantage of taking dimorphism ratio as an indicator of undernutrition is that it cannot necessarily differentiate between gender dimorphism and sexual dimorphism (11). Whereas men and women biologically differ in their nature of growth (sexual dimorphism), parents might favor sons over daughters since they are of more traditional, economic, and psychological value (12). This itself might result in gender dimorphism, as sons might be more often sent to doctors when they are sick and might receive a higher quantity and quality of food compared to their female siblings. Hence, diverging behavioral patterns among parents manifest in gender dimorphism of their children. However, previous research found that under nutritional stress, females biologically are more robust than males given their superior chromosomal constellation under dire living conditions (13-15). This apparently means that genetic or sexual dimorphism matters more in such situations and this will be elaborated on further in a later section.

Concerning data on chronic child undernutrition, this research makes use of the 'WHO Global Database on Child Growth and Malnutrition' maintained by the United Nations. This by far the most comprehensive database on stunting of children, despite the fact that it is surprisingly overlooked by scholars in the field. The WHO database dates back to 1986 when the German government funded a three year project at the Programme of Nutrition at the World Health Organization (16). After 15 years, the database had accumulated information from 846 surveys covering 99% of pre-school children in developing nations and 64% of their peers in developed nations (17). However, one drawback of the database is that it largely fails to report malnutrition rates in highly industrialized countries such as the United States or nations in the EU (see Table 2). This is a result of data unavailability since the surveys were oftentimes lacking or not available in standardized format. On the positive side, these wealthy nations more often have problems related to overnutrition rather than with growth retardation or undernutrition. The creation of the database served various purposes: "The WHO Global Database on Child Growth and Malnutrition illustrates malnutrition's enormous challenge and provides decision makers and health workers alike with the baseline information necessary to plan, implement, and monitor and evaluate nutrition and public health intervention programmes aimed at promoting healthy growth and development" (16). The primary objective of the project was to report standardized and reliable child undernutrition rates around the globe, following the recommendations of the WHO and National Center for Health Statistics (NCHS), in order to obtain anthropometric growth references of children since the late 1970s (6, 18). Data were drawn from the following sources: national statistics, published articles, and reports by NGOs and UN agencies. Additionally, surveyors were encouraged to submit their own anthropometric data for possible inclusion in the database. Overall, the quality of the data is excellent, as surveys had to be based on population or probabilistic sampling and consistency checks regarding the data were made afterwards.

As a healthy reference group, the United Nations World Health Organization recommended the US-American population ('NCHS/WHO child growth standards'). All surveys included in the global database were standardized by using these reference charts. Of note, the World Health Organization published revised standards in April 2006 ('WHO child growth standards'). Yet, these new reference standards have not been used much in applied research. In addition, the revised WHO Global Database on Child Growth and Malnutrition has not yet been replaced by new estimations for all of the countries. More importantly, this paper draws from a previous project on rural-urban malnutrition among pre-school children around the world (19). Data were retrieved from about December 2005 to January 2006, meaning that the original WHO/NCHS standards were used and not the revised ones. Thus, giving current time and funding constraints as well as considering that the new WHO reference standards are not really widely employed in applied research anyway, this paper draws on the 'old' database (as of late 2006) that was systematically assessed during a previous project (19) and re-employed in another paper focusing on a regional statistical outlier (20).

Table 2. Data coverage of chronic undernutrition

Countries		Continents and Subregions	Sample Size	Age group in years	Year of survey
1	Afghanistan	Asia (South-central Asia)	4846	0.50-2.99	1997
2	Albania	Europe (Southern Europe)	1111	0. -4.99	2000
3	Algeria	Africa (Northern Africa)	4107	0. -4.99	2000
4	Angola	Africa (Middle Africa)	5127	0. -4.99	2001
5	Argentina	LAC (South America)	91943	0. -4.99	1996
6	Armenia	Asia (Western Asia)	1463	0. -4.99	2001
7	Australia	Oceania (Australia- New Zealand)	1 mill.	2. -7.99	1996
8	Azerbaijan	Asia (Western Asia)	1564	0. -4.99	2000
9	Bangladesh	Asia (South-central Asia)	5421	0. -4.99	2000
10	Benin	Africa (Western Africa)	4061	0. -4.99	2001
11	Bhutan	Asia (South-central Asia)	2981	0.50-4.99	1999
12	Bolivia	LAC (South America)	5773	0. -4.99	1998
13	Bosnia and Herzegovina	Europe (Southern Europe)	2569	0. -4.99	2000
14	Botswana	Africa (Southern Africa)	2718	0. -4.99	2000
15	Brazil	LAC (South America)	3815	0. -4.99	1996
16	Burkina Faso	Africa (Western Africa)	3791	0. -4.99	1999
17	Burundi	Africa (Eastern Africa)	2584	0.50-4.99	2000
18	Cambodia	Asia (South-eastern Asia)	3372	0. -4.99	2000
19	Cameroon	Africa (Middle Africa)	1923	0. -2.99	1998
20	Central African Republic	Africa (Middle Africa)	2225	0. -4.99	1995
21	Chad	Africa (Middle Africa)	5034	0. -4.99	2000
22	China	Asia (Eastern Asia)	16491	0. -4.99	2000
23	Colombia	LAC (South America)	4060	0. -4.99	2000
24	Comoros	Africa (Eastern Africa)	3179	0. -4.99	2000
25	Congo, Dem. Rep.	Africa (Middle Africa)	4362	0. -4.99	1995
26	Costa Rica	LAC (Central America)	1008	1. -6.99	1996
27	Côte d'Ivoire	Africa (Western Africa)	1630	0. -4.99	1999
28	Djibouti	Africa (Eastern Africa)	n/a	0. -4.99	1996
29	Dominican Republic	LAC (Caribbean)	1821	0. -4.99	2000
30	Egypt, Arab Rep.	Africa (Northern Africa)	10193	0. -4.99	2000
31	El Salvador	LAC (Central America)	6523	0.25-4.99	1998
32	Eritrea	Africa (Eastern Africa)	5466	0. -4.99	2002
33	Gabon	Africa (Middle Africa)	3113	0. -4.99	2001
34	Gambia, The	Africa (Western Africa)	2552	0. -4.99	2000
35	Georgia	Asia (Western Asia)	3434	0. -4.99	1999
36	Ghana	Africa (Western Africa)	2570	0. -4.99	1999
37	Guatemala	LAC (Central America)	5415	0. -4.99	2000
38	Guinea	Africa (Western Africa)	1457	0.50-4.99	2000
39	Guinea-Bissau	Africa (Western Africa)	5383	0. -4.99	2000

Countries		Continents and Subregions	Sample Size	Age group in years	Year of survey
40	Haiti	LAC (Caribbean)	6176	0. -4.99	2000
41	Honduras	LAC (Central America)	5613	0.25-4.99	2001
42	India	Asia (South-central Asia)	24396	0. -2.99	1999
43	Indonesia	Asia (South-eastern Asia)	9227	0. -4.99	1995
44	Iran, Islamic Rep.	Asia (South-central Asia)	2536	0. -4.99	1998
45	Iraq	Asia (Western Asia)	13710	0. -4.99	2000
46	Jamaica	LAC (Caribbean)	574	0. -4.99	1999
47	Jordan	Asia (Western Asia)	4633	0. -4.99	2002
48	Kazakhstan	Asia (South-central Asia)	612	0. -4.99	1999
49	Kenya	Africa (Eastern Africa)	5917	0. -4.99	2000
50	Korea, Dem. Rep.	Asia (Eastern Asia)	4175	0. -4.99	2000
51	Kuwait	Asia (Western Asia)	12376	0. -4.99	1997
52	Kyrgyz Republic	Asia (South-central Asia)	1015	0. -2.99	1997
53	Lao PDR	Asia (South-eastern Asia)	1260	0. -4.99	2000
54	Lebanon	Asia (Western Asia)	494	3. -9.99	1997
55	Lesotho	Africa (Southern Africa)	2907	0. -4.99	2000
56	Liberia	Africa (Western Africa)	4532	0. -4.99	2000
57	Libya	Africa (Northern Africa)	4354	0. -4.99	1995
58	Macedonia, FYR	Europe (Southern Europe)	1101	0.50-4.99	1999
59	Madagascar	Africa (Eastern Africa)	3080	0. -2.99	1997
60	Malawi	Africa (Eastern Africa)	9322	0. -4.99	2000
61	Malaysia	Asia (South-eastern Asia)	5108	0. -4.99	1999
62	Maldives	Asia (South-central Asia)	706	0. -4.99	2001
63	Mali	Africa (Western Africa)	10099	0. -4.99	2001
64	Mauritania	Africa (Western Africa)	3554	0. -4.99	2001
65	Mexico	LAC (Central America)	8011	0. -4.99	1999
66	Mongolia	Asia (Eastern Asia)	5784	0. -4.99	2000
67	Morocco	Africa (Northern Africa)	3555	0. -4.99	1997
68	Mozambique	Africa (Eastern Africa)	2837	0. -2.99	1997
69	Myanmar	Asia (South-eastern Asia)	8081	0. -4.99	2000
70	Namibia	Africa (Southern Africa)	4123	0. -4.99	2000
71	Nepal	Asia (South-central Asia)	6409	0. -4.99	2001
72	Nicaragua	LAC (Central America)	6242	0. -4.99	2001
73	Niger	Africa (Western Africa)	4616	0. -4.99	2000
74	Nigeria	Africa (Western Africa)	8617	0. -4.99	1999
75	Oman	Asia (Western Asia)	13809	0. -4.99	1998
76	Pakistan	Asia (South-central Asia)	9248	0. -4.99	2001
77	Panama	LAC (Central America)	2049	0. -4.99	1997
78	Peru	LAC (South America)	10477	0. -4.99	2000
79	Philippines	Asia (South-eastern Asia)	24308	0. -4.99	1998
80	Qatar	Asia (Western Asia)	1180	0. -5.99	1995

Table 2. (Continued)

Countries		Continents and Subregions	Sample Size	Age group in years	Year of survey
81	Romania	Europe (Eastern Europe)	21156	0. -4.99	2000
82	Russian Federation	Europe (Eastern Europe)	562	0. -4.99	1995
83	Rwanda	Africa (Eastern Africa)	6491	0. -4.99	2000
84	São Tomé and Principe	Africa (Middle Africa)	1646	0. -4.99	2000
85	Senegal	Africa (Western Africa)	8294	0. -4.99	2000
86	Serbia and Montenegro	Europe (Southern Europe)	1519	0. -4.99	2000
87	Sierra Leone	Africa (Western Africa)	2201	0. -4.99	2000
88	Singapore	Asia (South-eastern Asia)	15477	0. -4.99	2000
89	Somalia	Africa (Eastern Africa)	3852	0. -4.99	2000
90	South Africa	Africa (Southern Africa)	1556	1. -4.99	1999
91	Sri Lanka	Asia (South-central Asia)	2531	0.25-4.99	2000
92	Sudan	Africa (Northern Africa)	18043	0. -4.99	2000
93	Syrian Arab Republic	Asia (Western Asia)	6262	0. -4.99	2000
94	Tanzania	Africa (Eastern Africa)	2821	0. -4.99	1999
95	Thailand	Asia (South-eastern Asia)	4178	0. -4.99	1995
96	Timor-Leste	Asia (South-eastern Asia)	4061	0. -4.99	2002
97	Togo	Africa (Western Africa)	3260	0. -2.99	1998
98	Trinidad and Tobago	LAC (Caribbean)	781	0. -4.99	2000
99	Tunisia	Africa (Northern Africa)	891	0. -4.99	1997
100	Turkey	Asia (Western Asia)	2677	0. -4.99	1998
101	Turkmenistan	Asia (South-central Asia)	2928	0. -4.99	2000
102	Uganda	Africa (Eastern Africa)	6074	0. -4.99	2001
103	Ukraine	Europe (Eastern Europe)	3736	0. -4.99	2000
104	Uzbekistan	Asia (South-central Asia)	2400	0. -4.99	2002
105	Venezuela, RB	LAC (South America)	321257	0. -4.99	2000
106	Vietnam	Asia (South-eastern Asia)	94469	0. -4.99	2000
107	West Bank and Gaza	Asia (Western Asia)	1242	0. -4.99	1996
108	Yemen, Rep.	Asia (Western Asia)	7501	0. -4.99	1997
109	Zambia	Africa (Eastern Africa)	5784	0. -4.99	2002
110	Zimbabwe	Africa (Eastern Africa)	2520	0. -4.99	1999

Notes: LAC = Latin America and the Caribbean.

Source: Global Database on Child Growth and Malnutrition (as of January 2006), cited in Guntupalli and Schwekendiek (19).

The global database covers both national and regional surveys. As of August 2002, the database comprised 412 national surveys and 434 sub-national surveys (17). As national findings might be unnecessarily biased by regional disparities in living conditions, Guntupalli and Schwekendiek (19) excluded all sub-national surveys, some of which merely covered one city or district. Moreover, the “Global Database is a dynamic surveillance system and new information is continually being collected, screened and entered, data collection can never be considered complete” (16:3). This means that sometimes several surveys for one country entered the database. However, Guntupalli and Schwekendiek (19) opted to collect malnutrition data referring to only one point in time. Panel analysis would have been certainly more interesting, but as a matter of data availability, an effective cross-sectional analysis was performed instead. The year 2000 was chosen as the reference year. This year was selected because the United Nations carried out many surveys under the ‘Year 2000 Goal of the World Summit Declaration for the Welfare of Women and Children,’ implying that most surveys were conducted around that time. Guntupalli and Schwekendiek (19) first collected all information from the database with respect to national surveys (see above), and if various national surveys were available for a given nation, they recorded the malnutrition data from the survey conducted closest to the reference year 2000. Eventually, the selected national surveys were from as early as 1995 to as late as 2002, implying that earlier surveys, with one study dating back to the 1960s, were discarded as well. Data coverage by year of survey is shown in Table 2. When assessing rural-urban disparities in child malnutrition, Guntupalli and Schwekendiek (19) drew on a sample size of up to 93 nations. However, the current paper is based on up to 110 countries (see Table 2) since male and female malnutrition was more often reported than rural or urban malnutrition in the database. Note that an analysis of rural and urban malnutrition by gender cannot be conducted as these subcategories were unfortunately not systematically reported. Further, note that the regional classifications of subcontinents and continents made in this paper were taken from De Onis and Bloessner (16), following United Nations geographic classifications. None of these classifications reflect a position held by the author of this study regarding the legal status of any country or territory or the delimitation of any frontiers.

Last but not least, it should be emphasized that almost all of the selected surveys from the global database were based on pre-school children, mostly from 0.00 to 4.99 years of age (see Table 2). This is an important finding as ethnic differences in human growth cannot be ruled out (21), even if the environmental impact is probably much larger. However, previous research successfully demonstrated that ethnic differences in growth among pre-school children do not matter (22).

As put by John Waterlow, an esteemed malnutrition expert: “The WHO/NCHS reference relates to healthy children. It is now widely, if not universally, accepted that children the world over have much the same growth potential, at least to seven years of age. Environmental factors, including infectious diseases, inadequate and unsafe diet, and all the handicaps of poverty appear to be far more important than genetic predisposition in producing deviations from the reference” (16: 1). Hence, even if ethnic differences in human growth mattered, they would firstly be less important than environmental factors, and secondly, they would be less pronounced among pre-school children (22).

For the later statistical analysis, stunting rates from the WHO Global Database on Child Growth and Malnutrition are regressed based on a set of socioeconomic variables. These data were borrowed from the World Bank (23) as well as from Freedomhouse.org, which measures political freedom around the world for various periods of time. Basing itself on a set of political subindicators, a nation’s political status falls into ‘free,’ ‘partially free,’ and ‘not free’ according to Freedomhouse.

FINDINGS

This section is divided into two parts. First, some descriptive analysis is carried out on the data to illustrate the prevalence of male-to-female childhood stunting according to world region. In the second half of this section, regression analysis is performed in order to provide some explanations for dimorphism around the globe.

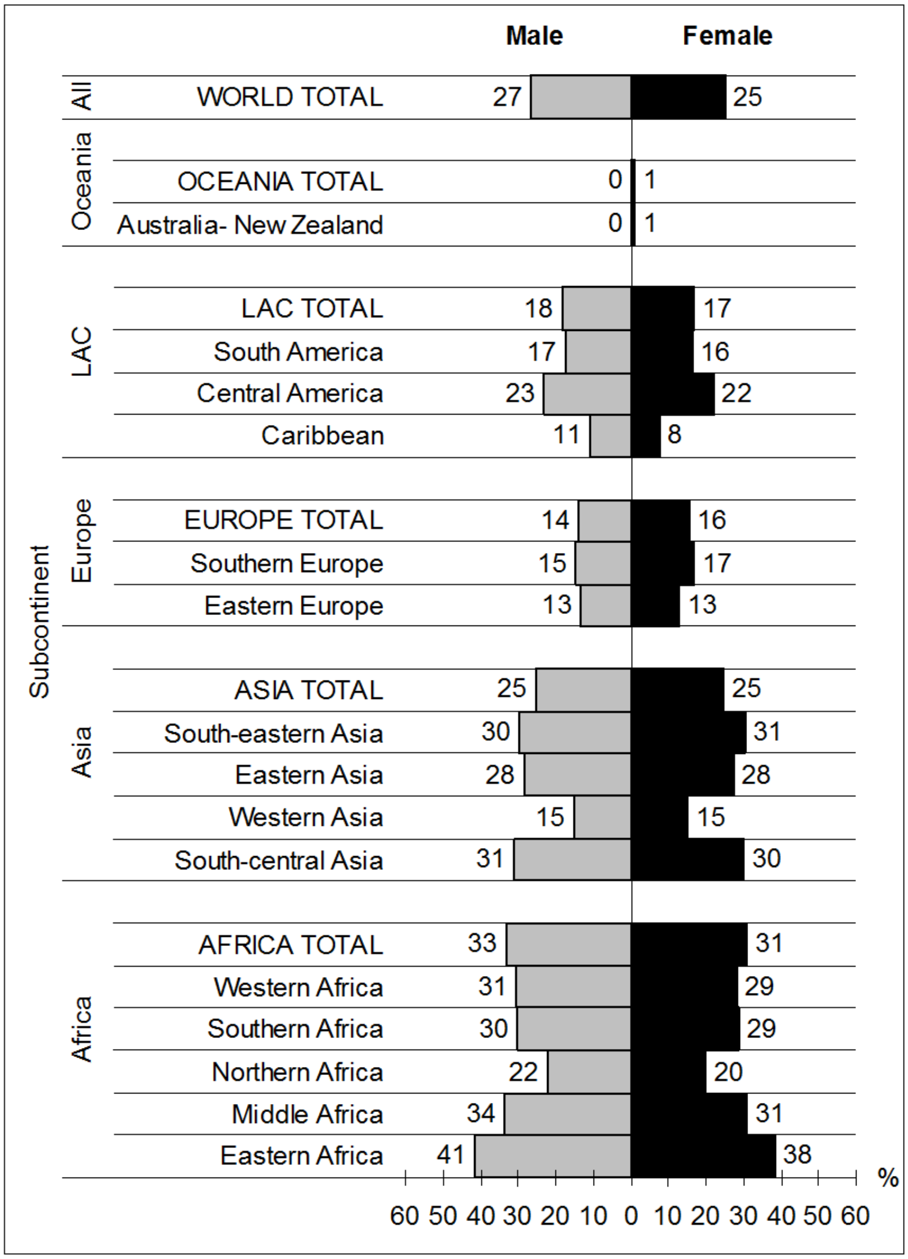

Figure 1. Dimorphism ratios of stunting by continent and subcontinent.

First of all, Figure 1 depicts a dimorphism pyramid. The world average of males suffering from undernutrition is 27% versus 25% for female peers, indicating that stunting is slightly higher among sons compared to daughters. We obtain a similar result when simply counting the number of national surveys that show a pro-female bias in terms of child stunting (Table 1). On a global scale, 83 national studies found that boys are more often stunted than girls (indicating a pro-female bias), whereas only 24 national studies found that girls are more often stunted in stature; three did found no bias against either gender. However, Figure 1 additionally indicates that there are regional disparities, with boys showing higher rates of stunting than girls in Latin America and the Caribbean (LAC) (18% versus 17%) or in Africa (33% versus 31%). On the other hand, girls suffer more often from chronic undernutrition than their male counterparts in Europe (16% versus 14%). By counting the number of studies finding a bias in favor of either gender and stratifying the results by subcontinent (see Table 1), a similar geographical pattern can be detected: boys in Africa and LAC more often suffer from undernutrition compared to girls. More importantly, in contrary to Figure 1, Table 2 suggests that stunting among boys is also higher in some Asian regions, which traditionally and ironically place more emphasis on sons than daughters. All these results tentatively suggest that sexual dimorphism matters more than gender dimorphism, casting doubt on the usefulness of anthropometric measurements such as height as an indicator of gender discrimination in society. To investigate statistical differences across continents (Table 3) and subcontinents (Table 4), analysis of variance (ANOVA) was performed. F-values were found at 2.84 and 5.36, and these were found to be statistically significant on the 0.01 percent level.

Secondly, dimorphism ratios can be regressed based on a set of variables that might explain these worldwide variations in gender-specific growth status. Following Coll (24), beyond genes, height (H) is a function of gross nutritional intake (N), the disease environment the child is exposed to (D), child labor (L), and biological maintenance (M). This gives the following equation: H = F (N, D, L, M). Assuming that most children are raised under stable climatic living conditions, the impact of M is negligible. Further, as this research is focused on pre-school children mostly 0.00 to 4.99 years of age (Table 2), child labor (L) should not bias our findings. This yields H = F (N,D), which means that net nutritional status as measured based on height is a function of gross nutritional intake and outbreak of disease, as the human body first allocates energy input to the latter before human growth can take place. Therefore, daily kilocalories per capita as well as health expenditures as a percentage of GDP are constituents of model 2 (see Table 5).

Beyond this, by following Guntuapalli and Schwekendiek (19), regression 2 controls for a set of political and economic factors (Table 5). However, to control for unobserved regional disparities as well as to determine whether or not there are statistically significant differences within regions, a set of subcontintental dummies is entered into the regressions. Model 1 (see Table 5) indicates that regions do not statistically differ from the reference category (Eastern Europe), except for Southern Europe and the Caribbean, which have significantly higher dimorphism ratios compared to Eastern Europe. Only Eastern Asia, South Central Asia, Western Asia, and Oceania have lower dimorphism ratios than the reference region, indicating that girls are more often stunted compared to boys, although the differences are statistically insignificant. Model 2 (see Table 5) additionally suggests that a higher supply of kilocalories significantly increases the dimorphism ratio, implying that stunting among girls relative to boys is lower. This suggests that higher gross nutritional intake is disproportionably beneficial for daughters, probably since parents tend to prioritize sons with regard to the intra-household allocation of resources when the food supply is scarce. Note that the number of observations in model 2 (Table 5) drops from 110 to 87 countries due to missing values among the independent variables entered into the regression. Overall, the two models can explain about 36% of the total variance in the dimorphism ratio, which is fairly high considering that a large number of relevant but unavailable variables such birth order or number of siblings are omitted here.

Table 3. One-way ANOVA of dimorphism ratios of stunting by continents

Continents	Mean	SD	SE	95% CI (Lower Bound)	95% CI (Upper Bound)	N
Africa	109.144	8.713	1.285	106.557	111.731	46
Asia	104.012	12.566	2.012	99.939	108.086	39
Europe	115.988	19.438	7.347	98.010	133.965	7
LAC	118.401	30.717	7.450	102.607	134.194	17
Oceania	100.000	.	.	.	.	1
Total	109.107	16.500	1.573	105.989	112.226	110

F = 2.838, $p < 0.05$.

Table 4. One-way ANOVA of dimorphism ratios of stunting by subcontinents

Subcontinents	Mean	SD	SE	95% CI (Lower Bound)	95% CI (Upper Bound)	N
Africa (Eastern Africa)	107.967	4.115	1.100	105.591	110.343	14
Africa (Middle Africa)	109.607	9.227	3.488	101.074	118.141	7
Africa (Northern Africa)	115.149	14.033	5.729	100.422	129.875	6
Africa (Southern Africa)	104.838	9.367	4.683	89.934	119.742	4
Africa (Western Africa)	108.773	8.960	2.313	103.811	113.734	15
Asia (Eastern Asia)	102.903	3.718	2.147	93.667	112.139	3
Asia (South-central Asia)	104.068	14.914	4.137	95.056	113.081	13
Asia (South-eastern Asia)	107.081	11.096	3.509	99.144	115.019	10
Asia (Western Asia)	101.851	13.029	3.613	93.978	109.724	13
Europe (Eastern Europe)	104.715	15.072	8.702	67.275	142.155	3
Europe (Southern Europe)	124.443	19.541	9.771	93.348	155.537	4
LAC (Caribbean)	159.909	40.193	20.096	95.954	223.865	4
LAC (Central America)	103.787	10.563	3.992	94.018	113.556	7
LAC (South America)	107.777	10.173	4.153	97.101	118.453	6
Oceania (Australia and Polynesia)	100.000	.	.	.	.	1
Total	109.107	16.500	1.573	105.989	112.226	110

F = 5.361, $p < 0.01$.

Table 5. Regression of dimorphism ratios of stunting

	1		2		
	Coefficient	t-value	Coefficient	t-value	
Intercept	**104.715**	**13.730**	**66.479**	**3.303**	▨
Gross Nutrition					
Daily kilocalories per capita			**0.010**	**1.773**	▨
Disease Environment					
Health expenditures as % of GDP			0.810	0.737	
Political Impact (ref.: not free)					
Free			2.776	0.533	
Partially free			1.260	0.032	
Economic impact					
GDP per capita			0.000	0.615	
Subcontinents (ref.: Eastern Europe)					
East Africa	3.252	0.387	18.150	1.527	
Middle Africa	4.892	0.537	18.900	1.529	
Northern Africa	10.434	1.117	15.559	1.304	
Southern Africa	0.123	0.012	6.494	0.505	
Western Africa	4.058	0.486	15.568	1.414	
Eastern Asia	-1.812	-0.168	5.430	0.376	
South Central Asia	-0.646	-0.076	3.764	0.332	
Southeastern Asia	2.366	0.272	9.719	0.860	
Western Asia	-2.864	-0.338	9.297	0.836	
Southern Europe	**19.728**	**1.955**	**29.892**	**2.339**	▨
Caribbean	**55.194**	**5.471**	**62.425**	**4.889**	▨
Central America	-0.928	-0.102	6.374	0.540	
South America	3.062	0.328	9.045	0.783	
Oceania	-4.715	-0.309	-5.826	-0.322	
Adjusted R²	**0.359**		**0.365**		▨
F	**5.361**		**3.604**		▨
N	110		87		

Note: Shadowed area: significance on the 10% level; the dependent variable is defined as: (share of male stunting / share of female stunting) x 100.

DISCUSSION

Anecdotal evidence and input indicators such as care of illness and food intake level suggest that daughters seem to be more disadvantaged with regard to the intra-household allocation of valuable resources. However, when it comes to output indicators of well-being, sons are more often reported to be stunted than females, even though they seem to be historically privileged and receive more food and medical provisions within the household compared to daughters.

This paper re-investigated worldwide gender disparities by conducting another meta-analysis of stunting rates. Therefore, this paper introduced a new and more comprehensive global data source that has not been used prior for this purpose. Descriptive analysis of the new data confirmed a previous meta-analysis that found that more sons than daughters are stunted. On the global scale, prevalence of stunting was found to be 27% among males versus 25% among females. Among 110 countries examined around the year 2000, a clear majority of studies (83 nations) found that girls had a better net nutritional status compared to their male peers (24 studies), though three studies found no bias against either gender. By using gender pyramids, this research found that stunting is higher in Africa and LAC, whereas the results are mixed for Asia. Furthermore, statistical regression analysis was conducted to identify which factors might impact male versus female stunting ratios around the globe. By controlling for a number of geographic, economic, and political variables as well as nutritional and health factors, this research found that increased daily calorie supply is disproportionably beneficial for daughters. This is probably because parents tend to prioritize sons regarding the intra-household allocation of resources when the food supply is scarce.

This research also tentatively concludes that sexual dimorphism, i.e., the female chromosomal advantage to overcome dire situations and nutritional stress, might largely explain the paradoxical finding that despite apparent son-preference among parents with regard to the intra-household allocation of resources, daughters seem to fare better than sons. This result has further implications, as anthropometric outcome indicators such as stunting rates are commonly applied in research as indicators of gender dimorphism. This research concludes that sexual dimorphism matters much more than gender dimorphism around the globe, casting doubt on the usefulness of anthropometric measurements as indicators of gender discrimination in society.

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Chapter 7

A CHILD WITH APRAXIA OF SPEECH AND AUTISM

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Children diagnosed with childhood apraxia of speech (CAS) often acquire sounds but have difficulties in putting them together and forming words. This case study deals with the therapeutic challenges and examines a technique called initial phoneme cue (IPC). A 10 year old girl with autism spectrum disorder (ASD) and CAS had word formation treatment for several years with no results. We compared the use of IPC technique versus regular imitation of CVCV structured words. Results: The use of IPC resulted in a 97-100% success of word imitation while regular imitation had 0-20% success of word imitation. Conclusions: The results confirmed our speculation of the efficacy of IPC's technique within this single treatment process.

INTRODUCTION

Initial phoneme cue (IPC) is a technique that is used for word formation among patients with Childhood Apraxia of Speech (CAS). Not many such techniques have been examined objectively in order to prove their usefulness in treatment of CAS in general let alone in the Hebrew language. An objective investigation of the IPC technique may provide clinical knowledge of the efficiency of the technique and may help in improving the technique's protocol. The purpose of this study was to assess the effect of the IPC technique of the Verbal Motor Learning (VML) method in teaching word formation among children diagnosed with CAS and Autism. I will begin by defining the CAS condition and scanning different techniques for treating difficulties in word formation and then concentrate on the IPC technique.

Childhood apraxia of speech (CAS) is a motor-speech disorder that occurs among children. This disorder is different from apraxia of speech (AOS) that occurs among adults

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after a head injury or cerebral vascular accident (1). The updated definition of CAS according to the ASHA (American Speech-Language-Hearing Association) is:

> “Childhood apraxia of speech (CAS) is a neurological childhood (pediatric) speech sound disorder in which the precision and consistency of movements underlying speech are impaired in the absence of neuromuscular deficits (e.g., abnormal reflexes, abnormal tone). CAS may occur as a result of known neurological impairment, in association with complex neurobehavioral disorders of known or unknown origin, or as an idiopathic neurogenic speech sound disorder. The core impairment in planning and/or programming spatiotemporal parameters of movement sequences results in errors in speech sound production and prosody”

Levelt et al. (2) distinguish between three different stages of speech and their pathologies, 1) impairments of lexical access to the word form (classic anomia), 2) phonological encoding (post lexical phonological disorder), and 3) phonetic encoding (apraxia of speech). CAS causes deficits in the production of consonants, vowels and the formation of words. Pronouncing a word built from two open familiar syllables can be a difficult task for a child with CAS (3). A common characteristic of word imitation among children diagnosed with CAS is a difficulty in pronouncing the first syllable of the word (4).

Shriberg et al. (4) identified segmental and supra-segmental characteristics of CAS. The segmental characteristics include (a) an articulatory struggle (groping) particularly on word onsets, (b) trans positional (metathetic) substitution errors reflecting sequencing constraints on adjacent sounds, (c) marked inconsistencies on repeated tokens of the same word type, (d) proportionally increased sound and syllable deletions relative to overall severity of involvement and (e) proportionally increased vowel/diphthong errors relative to overall severity of involvement. The supra-segmental characteristics include (a) inconsistent realization of stress (i.e., prominence on syllables or words), (b) inconsistent realization of temporal constraints on both speech and pause events and (c) inconsistent oral-nasal gestures underlying the percept of nasopharyngeal resonance. All of these characteristics of CAS effects word formation.

TECHNIQUES FOR TREATING DIFFICULTIES IN WORD FORMATION

A number of approaches and techniques have been introduced in the literature to deal with word formation. Tomlin (5) suggested forming words by practicing monosyllabic words and when the severity of the apraxia condition decreases the therapist should proceed to practicing multi-syllabic words. Tomlin (5) started teaching pronunciation by increasing phoneme control up to an 80% success rate of pronunciation. She argued that when the client starts to produce the phoneme correctly he/she will begin to understand the tactile/kinesthetic pattern of the phoneme.

Another approach is the cycles approach (6) which combines various phonological theories including cognitive psychology principles, phonological acquisition research and clinical phonology research. Its main purpose is to improve the speech pronunciation and clarity through planned cycles of pattern pronunciation targets which are based on seven underlying concepts.

There is also a technique that is called Metaphon which is a cognitive-linguistic treatment that aims to increase metalinguistic awareness as a means of improving phonological change and sound production (7). It is based on contrasting speech sounds and properties while emphasizing similarities and differences in sounds. It enables recognizing, matching and classifying sounds according to their features.

Finally, the “System for treatment of developmental verbal apraxia” (8) is a listed patent used to improve word formation among patients diagnosed with apraxia of speech. The system's kit includes a selected single-syllabic word cards in a specific order that forms a multi-syllabic word, which is also represented on a card. The multi-syllabic word is cut into single-syllabic sections that can be represented as words. The child is required to pronounce each single-syllabic section separately but in order so it superficially creates the multi-syllabic word.

THE INITIAL PHONEME CUE TECHNIQUE

One of the techniques that promote word forming among CAS patients is called initial phoneme cue (IPC) which involves prompting the first syllable of the word. IPC is usually used as a word retrieval technique for anomia, which is a problem in lexical access to the word form (9, 10). Ziegler and Wunderlich (11) found that the IPC technique was beneficial for children with CAS by shortening naming latencies. Hillis (12) argues that IPC can help in word retrieving for patients with Aphasia but the effect diminishes with time.

The IPC contains two kinds of information; auditory and visual. The auditory information leads the patient to the next phonemes of the word. The visual information shows the patient how to pronounce the first phoneme. Visual information from the speaker‘s face enhances intelligibility - in normal hearing conditions and, even more so, in noisy environments (11). Further information of how to exactly perform the IPC technique can be found in the appendix.

MOTOR LEARNING AND SPEECH

Speech involves complex motor movements and is the most complicated timed movement in the body. Each word production involves 100 muscles that need accurate and very fine tuning (13). The general motor learning principles can be applied to motor speech control in order to improve motor speech ability especially among patients diagnosed with CAS.

Knock et al. (14) investigated the application of a principle of motor learning (15), namely random practice and compared it to blocked practice as a mechanism to treat apraxia of speech in two patients, focusing on production of plosives and fricatives. Random practice is claimed to be more beneficial in terms of generalization and maintenance than blocked practice (15). In their study, Knock et al. (14) found that although trained practice sounds improved, there was no generalization to novel responses in either the random or the blocked condition. However, retention was better following random practice than following blocked practice. In addition, performance was less variable in random practice conditions than in blocked practice conditions.

The VML method (16) has been developed over the last 13 years in Israel in the Hebrew language. The beginning of the development was an intuitive field work with a 4 year old autistic child who also had CAS. The method has been expanded over the years using hundreds of different cases in a grounded theory research process (17). There has been subsequent development of treatment and evaluation tools, developing algorithms of the method, collecting data from hundreds of treatment processes and training therapists.

The VML is an organized, structured method that includes evaluation, analysis, techniques and treatment principles that promote speech via motor intervention. The system is based on two basic elements. The first is tactile and kinesthetic cues for every phoneme, syllable and word form. The second element is motor learning principles that enable thorough analysis and influence on the therapist's decision making process.

THE REASONING BEHIND THE IPC TECHNIQUE

In Hebrew, most of the words include two syllables or more. There are relatively few words built from one open syllable (CV format – consonant + vowel) and a larger group of words built form one closed syllable (CVC format). For a child diagnosed with severe CAS, the production of a single phoneme might be a difficult motor task so a CV format is even harder. A CVC format would require even more capabilities etc. Any combination of two phonemes together is two separate tasks which are difficult. At the beginning of the process the child can't handle so many motor tasks consecutively. The hierarchical process of the treatment is to build the ability to control the basic motor task (phoneme = consonant or vowel) by creating a motor scheme for each task. The second stage is to put two basic motor tasks together (consonant + vowel) to create a new motor scheme (open syllable, e.g., Ba, Gu, Ta). After creating the open syllable as a solid, controlled motor scheme the patient can move to the next level of putting two syllables together to build a more complex motor scheme. In Hebrew that will be his/her first complex word.

The IPC technique helps the patient to build a motor scheme of the format CVCV. The difficulty in imitating two open syllables is both phonological and motor. In the phonological aspect, the difficulty is to organize the chain of syllables in the correct sequence. A known phenomenon is backwards pronunciation that occurs at 2-3 years of age when the child put the syllables in backwards order. The motor difficulties evolve from the change in the articulator’s way of action and the quick timing needed for that. It can be manifest in different types of errors such as stopping, vowel replacement, vowel drop, consonant replacement etc. Not necessarily the specific error of a syllable pronunciation is syllable based problem if the same single syllable can be pronounced correctly not within the word formation.

In order to practice word formation the ability to pronounce each syllable within the word should be intact. The IPC unique strategy deals with the core problem itself – putting those two sounds together, while offering the precise support needed.

The purpose of this study is to examine the effect of the IPC technique according to the VML's protocol, in treating word formation among a child diagnosed with CAS.

CASE STUDY

The patient is a 10 year old girl diagnosed with CAS and autism from birth. She has a twin sister with normal development. The patient arrived at our treatment facility at the age of seven years after a few years of language and speech therapy. She progressed in several aspects of communication and language but there was no progress in her speech. She could not pronounce any phoneme or word through imitation or spontaneously even if she tried to. Her oral imitation and ability to blow out a candle or whistle were intact. There were spontaneous vocalizations and her hearing tests were in the normal range. She can read and write in Hebrew with no syntax mistakes which may point to intact auditory processing.

After a weekly 60 minute session of treatment over the first year in the facility, she acquired the ability to imitate all the phonemes and syllables separately but couldn't pronounce two syllables or more in a single utterance. Many different techniques were applied for at least two years with no success. The therapist then tried the IPC technique after obtaining informed consent from the patient’s parents.

Procedure

The patient was introduced to a list of 11 words built of two syllables (CVCV form). The patient was asked to imitate the word list under two conditions: A) Imitation without prompting, B) IPC technique. The procedure was administrated in an AB - BA format in order to eliminate order of presentation interference. Data was collected in two meetings, two weeks apart (first week – BA, second week - AB). In addition, a randomized observation of word pronunciation with and without the IPC support was made.

The examiner sat in front of the patient and asked her to imitate the words one by one. There was only one chance for the patient to reply in order to eliminate the influence of instruction by the examiner. If the patient wasn't focused and didn't listen to the examiner the test stopped until she regained focus.

Measurement

The dependent variable was a successful word imitation. Successful imitation is a dichotomy variable which is defined as success in pronouncing the utterance completely with all the right phonemes in the right order (not necessarily clear pronunciation). The tests were filmed and downloaded to the computer for analysis. The analysis is objective as the observer is only looking to see if all the phonemes are apparent and in the right order. However to enhance reliability of this measure, two separate observers watched the videos. The two observers produced 100% agreement in regards to this measure.

RESULTS

In the AB-BA procedure, all the trials without the IPC technique failed (0/22, 0%) while all the trials using the IPC technique were successful (22/22, 100%). In the randomized observation the results were similar. Trials without the IPC technique showed 20% success (6/30) while trials using the IPC technique showed 96% (24/25) success.

DISCUSSION

A word is the smallest structure in language while it is the end product of the speech process. The ability to construct a word of two or more syllables enables the child to use practical verbal expressive language, however, for some children this can be very difficult to accomplish. In this case we tried various techniques such as simple word imitation, manually assisted imitation, articulation prompting, C1VxC2 Vy/C2VxC1 Vy paradigm (e.g., :BaGu/Gabu), CV1 + CV2 imitation (imitation of the two syllables one after the other while decreasing the time between two imitations to minimum), over lapping technique (adding the second syllable in imitation while the child is still pronouncing the first one) , the techniques reviewed in the introduction and reading for over two years without success. The IPC technique was the first to have some effect on the ability to pronounce a CVCV format word with no support after the beginning of pronunciation.

The results were conclusive of the effect IPC has in this case. In the random trials there were few words the child could pronounce without support; those words consisted of the same consonant in the first and second syllable though the vowels differed (BUBA e.g.). Since the base of the consonant articulation was the same it was easier for the child to follow the structure. The unsuccessful imitations concluded in imitating the second syllable alone correctly.

I speculate that the IPC technique was useful here since it organized the word’s structure and components for the child by giving her the part that she missed most of the time (first syllable) but forced her to think and retrieve the second syllable by herself with no support. That mechanism intervenes with the actual process of word construction, while in a very “pointy” way forces the child to establish the ability she lacks. If each segment of the word is presented as in the “System for treatment of developmental verbal apraxia” (System for treatment of developmental verbal apraxia, 2012) or at Metaphon method (7), then the child might end up imitating single segments separately and not organizing the segments in the right order by herself as a whole structure. It is like reading the letters within the word without understanding the meaning of the word.

Two years after starting to practice the IPC (and five years after starting to practice speech) the child was able to imitate a variety of 2-3 open syllable words (cvcv – cvcvcv) with no support, and to use them spontaneously in conversation. The weekly session in our facility was the only intervention she had for speech during that time. It took a long time for her to imitate 2-3 syllables words due to the great problems she had, and due to the minimal practice time. It seems as though the IPC technique made an immense difference and enabled her to use a wide range of words to communicate verbally. However, the process is not finished yet as she doesn’t have good control over CVC word structures and other more complicated structures. These might take long time to accomplish, not to mention the work that needs to be done on expressive language.

This is a case study and thus the results should be interpreted with great caution. We will not necessarily observe the same results with other children diagnosed with CAS, although our experience shows a positive tendency. The next stage of this case study should be a randomized controlled trial of a large group of children diagnosed with CAS. Only then can we confirm the results we observed in this case and apply them with confidence in the professional field. Moreover, the technique should be tested in a prospective study in comparison to other techniques.

APPENDIX: THE IPC TECHNIQUE PROTOCOL

1. The therapist presents the word verbally in regular rhythm and in a visual way so the patient can see the visual cues. (e.g., “say uga” which is cake in Hebrew)
2. The therapist guides the patient to start with the first syllable by tactile cueing, asking him/her to do so, repeating the first syllable before the patient starts the imitation or by a visual cue.
3. If the patient started with the first syllable then the therapist will wait for the patient to produce the second syllable independently.
4. If the patient doesn't say the second syllable after 1-2 seconds or says an incorrect syllable the therapist will intervene using tactile cueing, repeating the second syllable or use by using a visual cue.

Motor aspects of the stages

Stage 1

The therapist presents the word verbally in regular rhythm so the patient can recognize the necessary timing needed for correct transfer from the first to the second syllable.

Stage 2

The first syllable of the word should shape the phonological sequence of the word. The last syllable of the word is the easiest to pronounce since it is the last to be heard and it’s phonological and motor memory is freshand easy to retrieve. In order to pronounce 2 open syllable word the patient needs to organize the first syllable as the first motor scheme to be executed even though it is not fresh in the memory. This procedure takes place only when the word is new and perceived as two separate motor tasks. When the word is known and the patient can pronounce it easily it is perceived as one motor task (i.e., one motor scheme).

Stage 3

It is very important to get the patient to the first syllable with all the support he/she needs and let him/her be active in organizing and recalling the second syllable. This is the main learning process and enables imitating and pronouncing complex words.

Stage 4

The expectation of the therapist shouldn’t be on giving the patient experience in solving the problems. The chances of the patient to succeed are low so if he/she will be measured upon successes as he/she will develop frustration and will not cooperate further. The therapist should intervene early in order to prevent frustration. The apraxic patient has problems in self-learning speech-motor tasks that are learned automatically by others from infancy. It sometimes takes hundreds of tries until he/she understands the movement in comparison to several attempts for a person with regular capabilities.

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Chapter 8

CHILD MALTREATMENT PREVENTION

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Child maltreatment is a significant public health problem, with almost 25% of all reports occurring in Latino families. Child maltreatment and intimate partner violence (IPV) often co-occur, and the sequelae of IPV frequently appear in the victimized mother and her children. Home visitation programs such as SafeCare® are intervention strategies to reduce the risk of child maltreatment, but these programs are rarely adapted for Latino populations. The importance of cultural sensitivity in parenting programs has been highlighted as a means of producing successful outcomes when working with Latino families. The present study includes multiple methods: a single-case research design study evaluated the effects of the SafeCare Parent-Infant Interaction (PII) module when delivered in Spanish to a Latino mother with prior IPV experiences; self-reported quantitative measures assessed exposure to IPV and changes in mental health, parenting stress, and the risk of child maltreatment; and qualitative data provided suggestions for culturally adapting PII for Latino families. Data from this study suggest that PII improves parent-infant interactions when delivered in Spanish and can reduce the risk of child maltreatment. Additionally, self-reported measures confirmed that IPV, parent mental health distress, and the risk of child maltreatment co-occur and can be reduced with PII. This study suggests the importance of providing culturally adapted programs when working with Latino families.

INTRODUCTION

Child maltreatment (CM), that results in harm or threat of harm by abuse or neglect, resulted in 676,569 substantiated victims in the United States (US) in 2011; seventy-nine percent of cases were attributed to neglect (1, 2). While CM was present in all ethnicities, the majority

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of reports occurred among White children (43.9%), followed by Hispanic (22.1%), and African-American (21.5%) children (2).

The highest risk of victimization occurred for children under age five (1). Parent characteristics, including poor mental health, young age, low socioeconomic status, poor parenting skills, substance abuse, poor social networks, personal history of CM, and presence of intimate partner violence (IPV) can increase risk of perpetration (2). IPV occurs in the form of physical, sexual and psychological harm by a former or current partner (3). With four out of five victims being women, the victimization rate for Hispanic women alone in 2010 was 4.1 per 1,000 compared to 6.2 per 1,000 in non-Hispanic White, and 7.8 per 1,000 non-Hispanic Black women (4).

IPV and CM often co-occur, with an estimated 30% to 60% of children who witness IPV also experiencing CM (5). Childhood exposure to IPV can lead to delayed cognitive development, behavioral problems, depression, anxiety, intrapersonal violence, and ultimately, premature death (6).

Prevention strategies for CM, such as home visitation programs, have been shown to prevent and reduce risk factors for CM while improving parenting skills, parental mental health (i.e., depression), and child health and development (7, 8).

SafeCare®, an evidence-based, parent-training home visitation program for families with children under five, is effective in improving parenting skills and reducing future risk for CM (8). SafeCare is delivered by a home visitor (HV) and consists of direct behavioral observations and skills training to predetermined performance criteria in three core areas: home safety, child health, and parent child/infant interaction (9). A six-year, statewide randomized-controlled trial with 2,175 families and 219 home visitors found significantly lower CM recidivism rates among families receiving SafeCare services when compared to families receiving services as usual (7).

Within the SafeCare model, parents with infants receive the Parent-Infant Interaction module (PII), the focus of the present study. In it, they learn to increase positive interactions with their infants, incorporating physical (touching, rocking, holding) and nonphysical (looking, talking, smiling, imitating) skills into daily routines. Additionally, they are taught to recognize developmental milestones, and acquire skills to plan daily play activities as their infant develops (9). PII has been validated by a single-case research design study only once (10), but unlike the other modules, the effectiveness when delivered in Spanish has not been evaluated (11).

CULTURE IN INTERVENTIONS

Latinos in the US are the largest and fastest growing minority; they are often underrepresented and not included in treatment and services research (12). Consequently, having neglected to consider treatment relevance to the target population leads to a disconnect between the intervention and the actual need of minorities (13).

Studies have demonstrated that culturally-adapted evidence-based treatments which adhere to fidelity standards are more effective and reduce drop-out rates (12). Such programs are those which provide services in clients' own language, are compatible with cultural norms, and have culturally competent providers (12). Thus, integrating parents' cultural background into parenting programs may affect more positive change in parenting behavior (14). Despite Latino parents' strong desire to learn about how to improve their parenting abilities, they report the lack of cultural sensitivity as the main obstacle for their participation (13). Interventions incorporating cultural adaptations to evidence-based parenting programs have been satisfactory to Latino families while producing positive treatment outcomes (15, 16).

Although SafeCare has been successful in multiple contexts, possible cultural adaptations have not been studied extensively. A sub analysis of data from a large statewide randomized controlled trial found that structured cultural adaptations were not necessary for the SafeCare model when working with American Indians (17). In other studies, parents have rated SafeCare as being more culturally-competent when compared to similar services (18). In a survey of current SafeCare providers, Self-Brown and colleagues (19) found the need to provide cultural sensitivity and competency training to its HV and creating Spanish translations of its parent materials. Providers also recommended that it is important to match families and HVs based on common culture and language in order to increase retention and acceptability of the program. Finally, providers suggested including an acculturation measure as part of the initial SafeCare session to deliver culturally appropriate services to families.

With regard to specific SafeCare modules, a single-case research design study was conducted to evaluate home safety, health, parent-child interaction training with Spanish-language delivery with one Spanish-speaking family (11). The intervention received high ratings from the family, and the data showed that the modules were delivered effectively in Spanish. Nevertheless, the Parent-Infant Interaction module of SafeCare has not been evaluated in a similar manner.

The purpose of the current research was to investigate how a Latina mother with prior exposure to IPV might improve parent-infant interaction skills through participation in the SafeCare PII module when delivered in Spanish using a single-case research design. Moreover, it examined how her participation in PII might affect her depression and other mental health symptoms, parenting stress, perceived protective factors, as well as the risk for CM as observed in self-report measures. Finally, this study aimed to survey the potential need for Latino cultural adaptations to the PII module. The mother provided feedback and suggestions on the program for developing a SafeCare PII curriculum that is culturally competent for Latino families.

OUR STUDY

One mother and her 12-month-old son were recruited after meeting the inclusion criteria: Latina mother between 18-40 years old with an infant under 12-months-old who was not ambulatory, interested in improving parenting skills, and currently participating in a program for Latino families affected by IPV. The participant was a 40 year old single mother of three from Mexico who had been living in the US for seven years. The language spoken in her home was Spanish. The highest level of education attained was a high-school degree, and she reported an annual income of $12,000.

The mother was recruited from an organization that provides direct services to Latino families affected by IPV, which she had been receiving for one year in support groups and individual counseling sessions. She had never previously participated in parenting classes. A bilingual researcher (first author; hereafter referred to as HV [home visitor]) conducted the study.

Although the mother was not living with a partner, research sessions were not conducted at the family's residence due to safety concerns as a result of the ex-partner's use of violence and fear that he might come back to the home. To facilitate the training, the referring organization provided the HV with private space in their facility to conduct all observations and training with no disruptions or distractions. The room was adapted to simulate a home setting with a living room-like space, and toys were brought in to be used during parent-infant interaction activities. Each session was held once per week and lasted an average of 45 minutes.

Parent materials used during training sessions were provided in Spanish. Words and themes that are not used in the Latino culture, for example "peek-a-boo" or lullabies and bedtime stories, were replaced with ones from the Latino culture. During each session, the HV also verbally incorporated concepts of the Latino culture into the training, such as beliefs and traditions during a child's development, as well as discussing parenting behaviors which are passed on from one generation to the next.

PII materials included cards containing information on developmental milestones, infant physiological states, description of interaction skills, and age-appropriate activities. The HV supplied toys to be used during PII activities, and the mother also brought several of her infant's toys that could be useful during the sessions, as well as any baby supplies she would need for that day. Parent self-report measures were administered using a laptop computer provided by the HV. The measures were delivered using Audio Computer Assisted Self-Interview (ACASI) software, which read individual questions aloud to the mother in Spanish and kept all answers confidential.

Observer training

All research staff were graduate research assistants and trained home visitors from the National SafeCare Training and Research Center (NSTRC). Training for the PII module consisted of didactic sessions during which NSTRC training specialists provided standard PII written materials. This was complemented by observations of pre-recorded videos of PII home sessions, role-play exercises, and feedback and discussions from the trainers. Training concluded with a written assessment of knowledge and skills, for which research staff obtained 85% or greater correct responses.

Dependent variables

Observational measure

Observers used the SafeCare infant Parent Activities Training (iPAT) HV Assessment form, on which partial interval recording was used to document the occurrence of seven parent skills during one play and two daily activities. The decision to observe certain daily activities was made by completing the Daily Activities Checklist (DAC) with the mother during the first session. This form lists daily routine activities, such as mealtime or diapering, and asks the mother to rate how much change is needed in each. Response options range from “a lot of change” to “no change” needed. Based on this form, the activities indicated to be the most challenging for the mother were chosen to be observed throughout the training. Each activity was observed for three minutes; a stopwatch was used to denote the observation intervals.

The seven parent skills included looking, talking, touching, smiling, imitating, rocking, and holding. The skills were separated and scored into two separate categories: physical skills (touching*, holding, rocking) and nonphysical skills (smiling*, looking*, talking*, imitating). Skills marked with an asterisk (*) were determined by NSTRC to be core skills and should be performed during any activity with a child. Conversely, noncore skills (holding, rocking, and imitating) are those in which it is not always possible to engage in during every activity with the child.

A check mark (✓) was used to indicate the occurrence of skills during each one-minute interval. Noncore skills were scored as “N/A” if observers agreed that in the context of the activity, the particular skill could not be performed. A percentage score for each cluster of skills was derived by dividing the total number of occurrences (✓) by the total number of intervals observed, and multiplying by 100.

Reliability

Interobserver reliability training occurred between the HV and a research staff member who served as the reliability observer (RO). Scores were compared by percentage agreement using the calculation: agreements/(agreements + disagreements) x 100. A satisfactory interobserver reliability score was 85% or above. A total of four training videos were observed, at which time the reliability score had reached the desired criterion.

Interobserver reliability was assessed in 43% of the sessions, which included baseline and training. During reliability sessions, both the HV and RO observed one play activity and two daily activities between the mother and infant. The HV and RO used the SafeCare iPAT sheet and scored independently.

Parent self-report measures

Six parent self-report measures were delivered using ACASI software in Spanish. The assessment was conducted during the first baseline session, upon completion of the intervention, and at the one-and three-month follow-up sessions.

Revised Conflict Tactics Scale, short form (CTS2)

The CTS2 measures the frequency of violent episodes in an intimate partner relationship over the past 12-months. Events are categorized into five subscales: negotiation, physical assault, injury, sexual coercion, and psychological aggression. Construct validity ranges are high for both perpetration of the behavior and victimization (20).

Brief Child Abuse Potential Inventory (BCAP)

The BCAP, a short form of the Child Abuse Potential Inventory (CAP), screens for the risk of parental child abuse by reporting on family conflict, feelings of persecution, distress, rigidity, happiness, loneliness, and financial insecurity. The BCAP yields similar results to the CAP, with correlations and internal consistency (21).

Multidimensional Neglectful Behavior Scale (MNBS-P)

The MNBS-P measures emotional, physical, cognitive, and supervisory parental neglect in children between the ages of birth and five. The scale has shown to have satisfactory to high levels of reliability and construct validity (22).

Brief Symptom Inventory (BSI)

The BSI provides a profile on nine primary symptom dimensions (Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism) and three global indices of distress (Global Severity Index, Positive Symptom Total, and Positive Symptom Distress Index). Internal consistency for subscales ranges is high (23).

Parenting Stress Index, short form (PSI)

The PSI measures stress in parent-child dyads based on parent and child characteristics, as well as life stressors, with high internal reliability (24).

Protective Factors Survey (PFS)

The PFS measures protective factors against CM in five different areas: family functioning and resiliency, social emotional support, concrete support, child development and knowledge of parenting, and nurturing and attachment. The survey has high internal consistency and subscale reliability (25).

Demographic and parent satisfaction survey

A demographic survey, created for the purposes of this study, was administered during the first baseline session to gather basic information on the mother's demographic characteristics, cultural variables, and parenting preferences. The standard SafeCare PII parent satisfaction survey, an 11-item, 5-point Likert scale, was administered upon completion of the intervention, prior to the follow-up session.

Semi-structured interview

A second bilingual research assistant with prior interviewing experience completed an audio-recorded semi-structured interview with the mother in Spanish at the end of the intervention, prior to the follow-up sessions. The purpose was to gather feedback and suggestions on the implementation of the PII module with Latino families, as well as to garner information on parenting and cultural variables that could inform the NSTRC regarding culturally appropriate services for Latino families.

Independent variable

During SafeCare PII training, the mother was taught the importance of engaging in each skill set, was trained on recognizing infant developmental milestones, and learned to engage in developmentally appropriate activities with her infant. Upon closing of each session, the mother was provided with additional activity materials that would allow her to practice the skills learned throughout the week.

Experimental design

A multiple-baseline design across behaviors was used to evaluate the effect of the PII training on parent-infant interactions. This documented the functional relationship between the intervention and targeted behaviors (26). The intervention is introduced in a staggered manner over a sequence of treatment conditions at different points in time, while the behavior is measured repeatedly within and across treatment conditions. Each participant, thus, serves as her own control, allowing researchers to document and compare behavioral performance pre- and post intervention. Data collected during observations are descriptive and predictive, guiding future intervention decisions (27). The relationship between the intervention and behavior is established once there is an observed stable trend in the desired direction with little or no changes in mean behavior performance, and there is an immediate effect in the dependent variable when the independent variable is modified (28). This mother was taught two clusters of parenting skills (physical and nonphysical) that she could perform with her infant during any activity. Intervention began first on the cluster of skills with the lowest baseline percentage score and which had remained stable. Once an ascending trend and high stable score was obtained for that cluster of skills, the intervention continued to the new cluster of skills.

Procedures

The study was approved by the Institutional Review Board at Georgia State University; at enrollment, the mother signed an informed consent document and was informed she would receive monetary compensation for her participation and would be able to keep all parent training materials used during the sessions.

At the beginning of each session, data collection occurred by observing the mother's interactions with her infant during one play activity and two daily activities (i.e., diapering, feeding, getting dressed, etc.), each activity lasting three minutes. The two daily activities observed throughout the training were chosen based on the DAC completed in the first session. The mother expressed that diapering and getting dressed were the most difficult two activities. The HV prioritized those activities during training sessions and were assessed in addition to other daily routine activities.

Baselines

Following enrollment, the HV completed the DAC with the mother, and collected the first baseline data. At the second baseline session, after behavioral observations and data collection was completed, the HV reviewed developmental milestones, physiological states of infants, including how to handle an upset baby, and how to plan age appropriate activities.

The mother completed the demographic survey during the recruitment session, and the computer-delivered interview during the first two baseline sessions.

Training

Nonphysical skills were the first skills taught, because they had the lowest score. Training began immediately after data collection for the last baseline session. After a stable data trend with high scores was observed in the nonphysical skills, training continued to physical skills. Each skill was taught using the "SafeCare 4" steps: Explain, model, practice, and feedback. The HV used SafeCare parent materials with a description of each skill and explained the skill and its importance, modeled the skill to the parent, asked the parent to practice, and provided positive and corrective feedback. After every session, the mother was asked to incorporate the skills learned into her daily activities and play activities.

When the data showed a stable high trend for all skills (80% or higher), the HV introduced the SafeCare child Planned Activities Training (cPAT) skills. These skills help prepare the mother interact with her infant as the child grows older, focusing on ways to increase positive interactions and prevent challenging behaviors. The mother was provided with skills on how to engage with her son before, during, and after a play activity (i.e., coloring, bathing). The HV and the mother picked one activity and practiced using the SafeCare 4 steps.

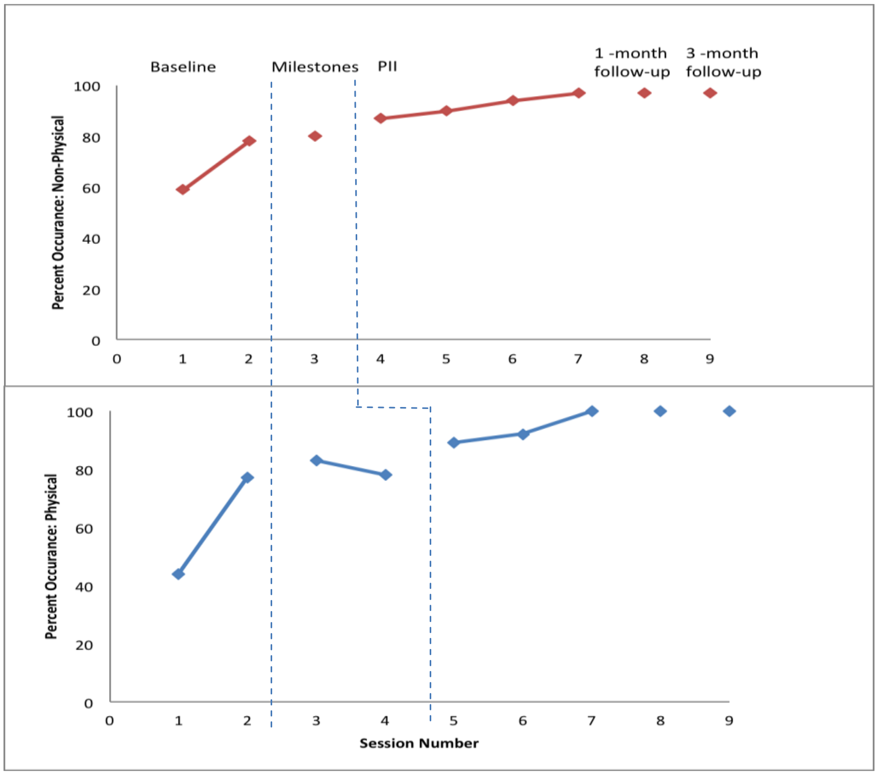

Figure 1. Percent occurrence of non-physical and physical skills.

Training ended once a stable trend was observed (at least three data points) with high percentages. At the end of the intervention, the mother was asked to complete the computer-delivered measures and the PII parent satisfaction survey. The mother also participated in the semi-structured interview at this time.

Follow-up

The mother participated in one -and three-month follow-up sessions during which data was collected on the mother's interaction with her child during three activities. She also completed the computer-delivered self-report measures.

FINDINGS

Figure 1 shows the percentage of parent demonstration of nonphysical and physical skills throughout the course of the intervention. Overall, introduction of infant developmental milestones and PII training produced an immediate increase in the mother's demonstration of nonphysical and physical interactions skills with her infant. The mean interobserver reliability score was 97.7% (SD = 2.52).

Baseline

Demonstration of predetermined interaction skills ranged from low to moderate during the two baseline sessions. Baseline scores for nonphysical skills were 59% and 78% during sessions 1 and 2, respectively, while physical skills scores were 44% and 77%, respectively. Both sets of skills showed an increasing trend at baseline, with higher scores for nonphysical skills. During session 2, developmental milestones were introduced, prior to the PII intervention.

Training

Although baseline data indicated an upward trend for both clusters of skills, intervention began on session 3 for nonphysical skills due to lower baseline scores and less stability when compared to the physical skills score. Upon introduction and training in PII nonphysical skills, there was an increase in percent occurrence from 80% in session 3 to 87% in session 4. Based on the improved demonstration of nonphysical skills, intervention was then implemented for physical skills in the subsequent session. Training on PII physical skills produced an increase in skills from 78% in session 4 to 89% in session 5.

During session 6, observing a stable trend with scores above 80% allowed introduction of Planned Activities Training. PII training concluded in session 7. At the final session, the demonstration of nonphysical skills had a score of 97% and physical skills had a score of 100%.

Follow-up

The mother actively engaged in nonphysical and physical skills with her infant at the one- and three-month follow-up sessions. The percent occurrence remained at 97% for nonphysical skills, and 100% for physical skills. Parent self-report measures were administered at pre-and postintervention, and at the one-and three-month follow-up sessions. As reported on the CTS2, over the prior 12 months the mother had experienced history of physical and sexual violence from her partner, and both had been psychologically aggressive towards each other. However, she also reported that both had engaged in some positive conflict negotiation tactics, indicating the use of conflict resolution alternatives to abusive or coercive approaches.

At baseline, there were two reports of neglectful behavior as measured on the MNBS-P, but no reports of neglect at post intervention and follow-up. The risk for child abuse, as reported on the BCAP, decreased from clinically-significant levels at baseline to normal limit scores at post intervention and follow-up.

BSI scores, measuring nine mental health symptoms, overall distress, and intensity of symptoms improved from clinically-significant levels at baseline to normal limit scores at post intervention and follow-up.

The PSI subscales of parental distress and total parenting stress decreased from clinically-significant levels at baseline to normal limit levels by follow-up. Both the Parent-Child Dysfunctional Interaction and the Difficult Child subscales remained at normal limit scores through all data collection points.

Scores on the PFS improved at post intervention and follow-up, demonstrating an increase in protective factors against child abuse and neglect.

Parent satisfaction survey and semi-structured interview

The mother completed the SafeCare PII parent satisfaction survey and participated in a semi-structured interview at the end of the intervention, providing suggestions on program characteristics and cultural adaptations that would benefit Latino participants. Overall, she rated her satisfaction with the PII module as very positive, and expressed gratitude for the opportunity to learn more about her son’s development and ways to interact with him, describing herself as someone who “tries to be updated on everything.”

The mother ‘strongly agreed’ that interacting with her infant had become easier, especially on routine activities, and would recommend this training to other mothers. She ‘agreed’ that now she had more ideas on how to interact with her infant, and indicated that she had applied some concepts learned during the sessions to her other children, stating that, “at home I have learned how to handle both [of] my youngest children.” Although she expressed a desire that sessions be longer, she shared that practicing during the sessions was useful and recommended that other people who live with her son, such as older children or grandparents, be present during training sessions.

She found the written training materials to be useful, and the translations and wording in Spanish “easy to understand.” The mother highlighted the importance of including Latino cultural adaptations in parenting programs. She provided suggestions for the written material, such as including Latino traditions and stories, as well as traditional Latino games that could be used to increase parent-infant interaction. Furthermore, she recommended providing additional detailed information on infant development and milestones as the child grows older, and learning more about “ways to express our feelings through games or songs or words” with our children.

The mother rated the HV as competent and friendly during the training, and saw this as an important requirement for any HV. She emphasized the importance of having a HV who understands the parent's culture and parenting practices, and described language ability as another important requirement for the HV.

When sharing her views on parenting in the Latino community, the mother explained that parenting is learned and passed down across generations; she learned many of her parenting practices from her mother. She also stressed that parenting culture in the US is very different from that of Latinos, and will shape how children are raised, suggesting that Latinos emphasize family relationships and warm personal interactions.

DISCUSSION

Single-case studies have validated the effectiveness of the SafeCare PCI, health, and home safety modules both English speaking and Spanish speaking families. However, delivery of PII in Spanish had not been evaluated, and neither had Latino cultural adaptations been explored.

PII was effective in improving parent-infant interactions as evaluated in this single-case study and when delivered in Spanish. There was considerable improvement from baseline in physical and nonphysical interactions between the mother and her infant, including at follow-up. These findings are further supported by the mother’s anecdotal comments that routine activities had become less challenging as a result of the training and practice during the sessions. Her anecdotal comments of applying learned concepts at home with her other children suggest generalization of learned parenting skills.

The SafeCare PII parent satisfaction survey added to previous data showing high satisfaction with the module and its components (18). In addition, the materials provided in Spanish were acceptable and easy to understand, indicating the need for SafeCare to use language-appropriate training materials. However, the mother's suggestions for adaptations when working with the Latino community should be noted. Programs that allow families to guide program development and dissemination increase the likelihood for behavior change, recruitment, and retention of families (29).

Latinos’ strong sense of community coupled with their strong sense of respect and value toward the family must also be considered in parenting programs. Familismo, a term used to describe attachment and sense of identity in Latino families, is observed in communal parenting and learned parenting behaviors as suggested by the mother (30). Therefore, considering other adult family members when delivering SafeCare to Latino families could lead to successful program outcomes.

In the present study, self-report measures were administered to record changes from baseline to follow-up, as well as augment anecdotal and observational data. These confirmed the co-occurrence of IPV, parental mental health distress, and CM. As reported by the mother, she had experienced a history of physical and psychological abuse, as well as sexual coercion over the past 12 months. Despite the sequelae of abuse, mothers who participate in home visitation programs have shown reductions in depression levels upon completion of the program (7). In this study, depression and other mental health distress symptoms were clinically elevated, but improved immediately post intervention.

Research suggests that children living in homes where IPV is present, and whose mothers are experiencing depression, parenting stress, or other adverse mental health symptoms are at higher risk of CM (2). This potential for CM was evidenced in this mother's elevated baseline BCAP, MNBS-P, and PFS scores, all which improved at post intervention and follow-up sessions. This improvement could be a direct result of her acquisition of proper parent-infant interaction skills through her participation in SafeCare. This was also seen in the direct behavioral observations, which has been demonstrated to be effective in reducing risk factors for CM (8).

While the findings of this study are promising and noteworthy, there are several limitations. It was conducted in a controlled clinical setting; behavioral observations could have differed had it been conducted in a home setting. Given that only one subject participated in this study, more research is needed to validate the mother's perspectives and suggestions on cultural adaptations of PII for the Latino community. Although improvements were observed in the parent's mental health state as well as protective factors against CM, it is not possible to know whether this was a direct result of the her participation in PII or other factors, such as weekly counseling sessions or participation in support groups. Further, it is not possible to know whether the mother's experience of IPV (as reported on the CTS2),or presence of adverse mental health symptoms had a direct effect on the risk of CM. Future studies with more participants should focus on examining the relationship between the different scaled measures and parents' participation in PII.

It is important to continue to examine how to best adapt the entire SafeCare curriculum for the Latino community. As suggested by the mother, SafeCare needs to ensure that the program is delivered in the parent's primary language by a HV who is trained on cultural competency, which is now being done in several communities in the United States. It is important to match HV and families on cultural background, as well as deliver SafeCare in the parent's primary language. SafeCare would benefit from providing a culturally-adapted program for parents that would include family members into training sessions (i.e., older siblings, grandparents), as well as Latino-specific traditions in its training materials. This will likely lead to increased parent engagement and program success (12). Program adaptations for Latinos living in the U.S. will differ from those for Latinos living in Latin America. If this program is to be implemented in Latin America, it is important to first study the uniqueness and richness of the culture.

Despite its limitations, this study adds to the large body of evidence for the effectiveness of SafeCare in reducing the risk of CM by improving parent-infant interactions. This study has also added to the knowledge that all modules of SafeCare can be delivered effectively in Spanish, and that appropriate Latino cultural adaptations could enhance the delivery and outcomes of the program.

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Chapter 9

NUTRITIONAL EDUCATION PROGRAM TO REDUCE OBESITY

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Children in the United States are on a pathway to live shorter lives due to the increased prevalence of lifestyle factors associated with obesity. Intervention programs implemented to reduce this trend do not adequately address the importance of parental involvement. Therefore, the purpose of this chapter was to examine the effectiveness of a child-only (i.e., control) versus a child-plus-parent (i.e., experimental) nutritional education program in reducing risk factors associated with childhood obesity. Four risk factors associated with childhood obesity were examined: knowledge of nutrition, dietary behavior, physical activity behavior, and sense of self-efficacy. Participants (N = 176) were second and third grade low-income students from a school in the Western United States. A self-reported survey was conducted in the participants' classrooms one week prior to the intervention (pretest) and one week after the intervention (posttest). Findings indicated that nutrition knowledge and self-reported dietary habits significantly improved in both control and experimental groups. Physical activity behaviors did not change from pretest to posttest for participants in either groups. However, parental education improved participant self-efficacy, where a child's willingness to ask their primary caregivers to buy fruits and vegetables increased significantly. Nutritional education within school programs positively impacts nutritional choices irrespective of parental input. Furthermore, programs designed to increase youth self-efficacy could play a role in attenuating childhood obesity and its attendant societal costs.

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INTRODUCTION

Childhood obesity is a costly public health issue. It is linked to the onset of many chronic diseases (1) and results in an expected decrease in longevity (2). Childhood obesity rates have steadily risen over the past 25 years, from 5% in 1976 to 15.5% in 2000 (3). This trend continues to worsen; in 2003-2004, 37.2% of children age 6-11 years, and 34.3% of adolescents age 12-19 years were considered overweight or at risk for becoming obese (4).

Numerous factors have been linked with the trend for increasing weight in the American population; however, poor dietary and physical activity habits remain primary. With respect to children, such decisions are often made by the parents, guardians, or others responsible for the child's welfare (from hereto forth referred to as parents) who exert control over the environment (5).

Many child-only focused school-based obesity prevention programs are ineffective in altering weight status (6). Summerbell and colleagues (6) suggest that nutrition education and physical activity interventions are successful in promoting healthful lifestyle choices such as fruit and vegetable intake and regular physical activity. However, future studies and programs should focus on the child's environment including the types of foods available at home, as this is the primary source of nutrition for most pre-adolescents (7-9). Thus, the first steps to evoke a permanent healthful lifestyle change are to increase awareness and knowledge and then to encourage and support an overt behavioral change through environmental support. When planning nutritional interventions among children and youth, it is important that parents are involved.

Dietary choices develop early (10-11); therefore, a school-based nutrition education intervention may be an effective way to prevent childhood obesity by lowering obesity risk factors. Children spend at least six hours each day in school, so school-based nutrition education interventions may help in reversing these trends. Current school-based nutrition education interventions focus primarily on increasing nutrition knowledge, promoting dietary changes, and increasing physical activity. Few researchers who have conducted initial study interventions designed to address childhood obesity are evaluating their programs, and even fewer are reporting their findings (6). Moreover, those that do show only mild and short-term improvements in changing behaviors associated with obesity risks. Only a few intervention studies have included a direct focus on educating parents, considered the most influential individuals in a child's environment (6). Townsend et al. (9) have suggested that future studies and programs should focus on the child's environment, including the types of foods available at home. Continual education and promotion are expected to alter health habits on an individual basis, leading to a societal change.

The concept of social change begins with an understanding of how a change in the environment can affect an individual's behavior and thus, in time, impact our society as a whole. It is therefore crucial to understand the history and process of change in societal environments such as families, communities, and social relationships if there is to be a chance to evoke a change in individual behaviors. Finally, the awareness and importance to health and nutrition professionals as a change agent is essential to promote this societal shift.

A number of peer-reviewed articles have revealed and confirmed the need to investigate a variety of possible solutions to this potentially devastating problem (12-13). This study explored one possible solution addressing the need to reduce obesity risk factors. For example providing targeted nutrition education in a child's classroom. Variables selected to be assessed for this study included: (a) increasing nutrition knowledge, (b) improving dietary behaviors, (c) increasing physical activity, and (d) improving self-efficacy. Two behavioral change models were used to structure this study: the health belief model (HBM)(14) and the social ecological model (SEM)(14). The HBM includes Bandura's (10) concept of self-efficacy, which is a key component that was assessed through pre/post test questions. The SEM includes valuable constructs relating to environmental influences associated with weight maintenance. Finally, social change, suggesting that individual change and social change are not mutually exclusive. A blending of simultaneous individual, environmental, and social changes are needed to evoke, foster, and support the elements necessary to reduce obesity risks among Americans.

Current evidence suggests that child-only nutrition education increases nutrition knowledge, but education alone has been ineffective in initiating and sustaining behavioral change. Therefore, the purpose of this study was to compare the relative effectiveness of two educational approaches to changing children's knowledge of nutrition, dietary behavior, physical activity behavior, and sense of self-efficacy. It was hypothesized that simultaneous parental nutrition education would improve a child's willingness to adopt a more healthful lifestyle and strengthen the child's self-efficacy score regarding ability or willingness to ask for fruits and vegetables, as compared with a child only nutrition education intervention. This study examined the effects of intervention on obesity risk factors among low-income children, not by measuring anthropometrics, but by comparing the relative effectiveness of two educational approaches. The goal of the two educational approaches was to positively affect known obesity risk factors among low-income second and third grade elementary school children through nutrition education designed to initiate healthful lifestyle changes.

OUR STUDY

Participants were 176 students (male: 99, 56.2%; female: 77, 43.8%) attending a low-income school site in a rural area of the Western United States. The school was a title one school, determined high risk for obesity and obesity related diseases based on weight status. Low-income is defined by qualification for a free or reduced breakfast and lunch. Just less than half of participants (87, 49.4%) were enrolled in third grade, and the remaining participants (89, 50.6%) were enrolled in second grade (see Table 1).

Based on a comprehensive review of the literature, four existing validated instruments were selected to measure the four major outcomes (knowledge of nutrition, dietary behavior, physical activity behavior and self-efficacy) of the intervention study. To measure knowledge of nutrition, the Reading Across My Pyramid (RAMP) quiz was selected (15). This quiz is part of the RAMP curriculum designed and utilized by the University of California Cooperative Extension (UCCE) Division of Agriculture and National Resources. The RAMP curriculum is used to educate lower level elementary school children on the Dietary Guidelines for Americans (i.e., MyPyramid/MyPlate). Only selected portions of the RAMP education were chosen to measure change due to the time design of the study and classroom time availability. The RAMP lessons have been designed to be used independently from one another. The design allows for greater flexibility for the classroom teachers to incorporate the

RAMP lessons into their existing teaching material. A total of 23 multiple choice questions were used to assess knowledge of nutrition.

Table 1. Sample characteristics

Variable	Child Only		Child-Plus-Parent		Total	
	#	%	#	%	#	%
Female	37	44.6	40	43	77	43.8
Male	46	55.4	53	57	99	56.2
2nd grade	43	51.8	46	49.5	89	50.6
3rd grade	40	48.2	47	50.5	87	49.4

RAMP questions typically used both word and picture choices to assess respondent's knowledge in food guide pyramid (MyPlate), vegetables, fruit, snacks and exercise. Sample questions included: "Which food should you eat more of?"; "Which beverage should you drink less of?"; "Which food belongs in the vegetable group?"; "What is the healthiest drink when you exercise?." This RAMP quiz has been shown to be valid and reliable and was designed for low-income kindergarten through third grade students (15). Based on the work of Heneman et al. (15), a score on the RAMP quiz indicated a participant's knowledge of nutrition by using the number of correct answers.

To measure dietary behaviors, the A Day In the Life (DILQ) 17-item instrument was used (16). The DILQ instrument measures the number of times a child eats fruits or vegetables during the course of a day. This 17-item instrument has been shown to have good reliability and validity and was designed for children of age seven to nine years (16). The questions utilize a 24-hour recall method of obtaining dietary intake. Sample questions are: "Did you have something to eat and drink for breakfast?"; "Did you eat or drink anything on the way to school?"; "Did you have anything to eat or drink at morning break?"; and "Did you have anything else to eat or drink between your evening meal and before you went to bed?." The questionnaire does not measure other dietary behaviors that may lead to obesity, such as eating empty calories and eating between meals. The study used fruit and vegetable intake as an indicator of healthy eating. Following the work of Edmunds and Zeibland (16), a study participant's dietary behavior was represented by the score of the DILQ, which is the number of times the participant eats fruits or vegetables during the course of a day.

Physical activity behavior was measured using the GEMS Activity Questionnaire, developed by Baranowski and colleagues (17) to measure physical activity behaviors for a nutritional education intervention. It has been shown to be valid and reliable for middle childhood age (age 8 to 10 years) respondents in measuring physical activity behaviors (18).

The GEMS Activity Questionnaire lists 28 activities typically performed by children, along with pictures of the activities. For each activity, respondents were asked to check off whether they engaged in that activity yesterday, and duration was ascertained by none, less than 15 minutes, or 15 minutes or more. They also were asked whether they usually take part in the activity, which was ascertained by none, a little, or a lot. Based on the work of Treuth et al. (19), a study participant's physical activity behavior was represented by two scores: 1) a score of activities performed yesterday, and 2) a score of usual activities. Scores were weighted according to intensity level of the activity using appropriate Metabolic Equivalent of Task (MET) values for children for each of the 28 physical activities (19-20).

To measure self-efficacy, the self-efficacy survey of “Asking and Shopping for Fruits and Vegetables” was selected (17), as it was developed to measure self-efficacy in the area of whether the child will be more likely to ask for fruits and vegetables and to put them on the family’s shopping list (17). It consists of eight five-point Likert-scale items. The respondent’s self-efficacy is assessed through an overall question “How sure are you that you can” in each of the eight items, such as “write my favorite fruit or vegetable on the family’s shopping list,” “ask someone in my family to buy my favorite fruit or vegetable,” “go shopping with my family for my favorite fruit or vegetable,” and “pick out my favorite fruit or vegetable at the store and put it in the shopping basket.” The responses were coded as 1: I’m sure I cannot; 2: I don’t think so; 3: I am not sure; 4: I think so; or 5: I’m sure I can. The reliability coefficient (Cronbach’s alpha) of the self-efficacy “Asking and Shopping for Fruits and Vegetables” measure for the current sample was 0.87 at pre-test and 0.82 at post-test. As reliability for all the other measures was established in previous studies, no reliability assessment on these other measures were reported in this study. Results from a small scale pilot study indicated that the testing instrument could be used to assess self-efficacy among the study population. Therefore, this served as an appropriate measurement in determining a child self-efficacy concerning how confident the child is about asking for fruits and vegetables to be included on his or her family’s shopping list (17).

Procedure

In an effort to protect the identity of the participants and ensure confidentiality, identification codes were assigned during the pre-testing period. In addition, no invasive or direct physical measuring or weighing was necessary for this type of study design. Furthermore, the study curriculum was administered by the classroom teacher and was incorporated as part of the school’s curriculum.

Following IRB approval, permission from school principal, parental consent, and student assent forms were collected respectively before any data collection began. First, a small-scale pilot study using 20 students was conducted to determine if the selected data collection instruments could be completed by the target age group study participants. Because not all instruments have been administered to second grade students, the pilot study assisted in determining whether questions could be understood and be completed through a self-administered survey approach.

Following the pilot study, eight classrooms (four second grade and four third grade) were recruited for the intervention study. After all recruited classroom teachers attended the required training and orientation meeting, all potential student participants were asked to take part in the nutrition education intervention. All potential student participants’ parent(s) were sent an informational package to inform them of the intervention study and asked to take part in the adult educational component. After parental consent forms were collected, child study participants were randomly placed in to one of two study groups (child-only or child-plus-parent education groups). Because the selected RAMP curriculum had been adopted by the participating school’s principal, the RAMP material was administered to all students by the classroom teachers. Given that children in both the control and the experimental group received the same intervention (RAMP curriculum), having children in both groups in the same classroom was not a concern. Parents of the experimental group received the adult nutrition education material while parents of the control group did not receive the curriculum.

For both the child-only education and child-plus-parent education groups, data collection was conducted one week prior (pretest) and one week following the intervention (posttest). Data collection took place in the students' individual classrooms, during class time, with the help of the classroom teachers. All teachers recruited for this study were required to attend a one day teacher training workshop to review the study and data collection procedures. This workshop was designed to introduce the teachers to the RAMP curriculum and to review the educational material.

Participants in both groups were asked to complete a questionnaire that included items about the four outcome measures during the pretest and posttest. As an intervention, children in both the control and experimental groups received five lessons from the RAMP curriculum over an eight week period which allowed teachers some flexibility to incorporate the content into their existing lesson plans. Lessons included selected portions from the chapters covering the Food Guide Pyramid (lesson 1), vegetables (lesson 3), fruits (lesson 4), snacks (lesson 7), and physical activity (lesson 9) (15). Parents in the experimental group received additional nutritional education information packets similar in content to the students lesson based on the USDA Dietary Guidelines for Americans.

FINDINGS

The main focus of this study was to determine and compare the relative effectiveness of two education approaches to changing children's knowledge of nutrition, dietary behavior, physical activity behavior, and self-efficacy.

Knowledge of nutrition (RAMP)

To determine differences between groups and knowledge of nutrition, measured using RAMP, a 2 (pretest/posttest) x 2 (child-only/child-plus-parent) repeated-measures ANOVA was conducted, using the knowledge of nutrition scores as the dependent variable and the educational approach as the independent variable.

Group variances were homogenous for both pretest scores and posttest scores, and Levene's statistic was not significant for pre or posttests. For pretest scores, the Levene statistic was 1.60 with $df_1 = 1$, $df_2 = 174$, $p > .05$. For posttest scores, the Levene statistic was 3.70 with $df_1 = 1$, $df_2 = 174$, $p > .05$. The ANOVA results revealed a non-significant main effect for Group [F (1, 174) = 0.30, $p > .05$, $\eta^2 = .59$]. That is, there was no significant difference in knowledge scores between the child-only group and the child-plus-parent group. However, there was a significant main effect for Time [F (1, 174) = 65.68, $p < .001$, $\eta^2 = .27$] where knowledge scores at the posttest (M = 20.65) were significantly higher than the pretest (M = 18.97). There was no significant interaction effect between Time and Group [F (1, 174) = 0.05, $p > .05$, $\eta^2 = .00$]. Dietary Behavior (DILQ).

To determine whether children receiving child-plus-parent nutritional education demonstrated a significantly greater improvement in dietary behavior than children receiving the child-only nutritional education, a 2 (pretest/posttest) x 2 (child-only/child-plus-parent) repeated-measures ANOVA was conducted, using dietary behavior scores as the dependent variable and the education approach as the independent variable.

Results from the test of homogeneity of variances show that group variances were homogenous for both pretest scores and posttest scores, where Levene's statistic was non-significant for both pre and posttest. There was no significant main effect for Group [F (1, 174) = 3.27, $p > .05$, $\eta^2 = .02$] where there was no significant difference in dietary behavior scores between the child-only group and the child-plus-parent group. However, there was a significant main effect for Time [F (1, 174) = 41.45, $p < .001$, $\eta^2 = .19$] where posttest dietary behavior scores (M = 2.35) were significantly higher than pretest (M = 1.44). The interaction (Time x Group) effect was not significant [F (1, 174) = 2.28, $p > .05$, $\eta^2 = .01$].

Physical activity

To determine whether children receiving child-plus-parent nutritional education would be significantly more physically active than children receiving child-only nutritional education, a 2 (pretest/posttest) x 2 (child-only/child-plus-parent) repeated-measures ANOVA was conducted, using physical activity scores as the dependent variable and the education approach as the independent variable. Group variances were homogenous for both pretest scores and posttest scores and Levene's statistic was non-significant for pre and posttests. There was a non-significant main effect for Group [F (1, 174) = 0.48, $p > .05$, $\eta^2 = .00$]. That is, there was no significant difference in physical activity (yesterday) scores between the child-only group and the child-plus-parent group. Main effect for Time and the interaction effect between Time and Group were both non-significant, respectively [F (1, 174) = 0.19, $p > .05$, $\eta^2 = .00$; F (1, 174) = 1.79, $p > .05$, $\eta^2 = .01$].

Self-efficacy

To determine whether children receiving child-plus-parent nutritional education showed significantly greater improvement in self-efficacy than children receiving child-only nutritional education, a 2 (pretest/posttest) x 2 (child-only/child-plus-parent) repeated-measures ANOVA was conducted, using the self-efficacy scores as the dependent variable and the education approach as the independent variable.

Group variances were homogenous and Levene's statistics for both pretest scores and posttest scores was non-significant. The main effect for Group was not significant [F (1, 174) = 1.08, $p > .05$, $\eta^2 = .30$], where self-efficacy scores did not differ between the child-only group and the child-plus-parent group. There was a significant main effect for Time [F (1, 174) = 28.29, $p < .001$, $\eta^2 = .14$] whereby self-efficacy scores at the posttest (M = 32.22) were significantly higher than the pretest (M = 28.87). Furthermore, there was a significant interaction between Time and Group [F (1, 174) = 4.69, $p < .05$, $\eta^2 = .03$]. A post-hoc comparison indicated a significantly larger increase in the self-efficacy scores for the child-plus-parent group than for the child-only group.

Results from the intervention study show that nutrition knowledge, self-reported dietary habits, and self-efficacy all improved for both the child-only and child-plus-parent education groups. Physical activities, however, did not change from pretest to posttest for either group. There was no significant difference in the improvement of nutrition knowledge and self-reported dietary habits between the child-only group and the child-plus-parent group. However, self-efficacy increased significantly greater for the child-plus-parent group than the child-only group.

DISCUSSION

This study examined the relative effectiveness of a child-only approach compared to a child-plus-parent approach to teaching nutrition principles that might reduce risk factors associated with childhood obesity among low-income second and third grade children. The focus of this study was to explore the potential differences in the effect of a child-only education intervention versus a child-plus-parent education intervention on four primary factors associated with weight status: knowledge of nutrition, dietary behavior, physical activity behavior, and sense of self-efficacy.

The study confirmed two assumptions, unverified one conjecture, and affirmed one new phenomenon. Knowledge increased with education, and self-reported dietary habits improved with the intervention. Physical activity improvements were not confirmed with this intervention. However, self-efficacy scores centered on healthful dietary intake increased with environmental family support. Although there were no significant differences in the improvement of nutrition knowledge and self-reported dietary habits between the study groups, self-efficacy scores increased significantly in the intervention group which perhaps suggests that parental involvement can empower a child to seek out healthful foods.

It remains unclear whether educating a child at school, in his or her own educational environment, helps to prevent the child from becoming overweight or obese. Furthermore, it remains to be seen whether educating the child’s parents to support a healthful lifestyle evokes a positive outward behavioral change that favors a healthful lifestyle in time to prevent these children from becoming obese, post-pubescent adults. What is now clear is that outward behavioral change begins with knowledge and a belief in one’s ability to make change. The outcome of this study did support Bandura’s (10) belief that after knowledge, self-efficacy is the next step to evoking a positive outward behavioral change.

Obesity trends and the associated diminished quality and duration of life have reached epidemic proportions, according to the Centers for Disease Control and Prevention (21). In order to establish life-long healthful dietary and physical activity habits, early health education and intervention are essential. Bandura (10) established that “Lifelong health habits are formed during childhood and adolescence” (p. 28). This study was designed to measure whether parental education improves a child’s outward behaviors to foster a more healthful lifestyle. The overarching outcome of this study suggests that of the four tested variables, only a child’s self-efficacy score significantly improved with informed parental influence. Age and cognitive ability posed the greatest limitations for the study given the selected population. This outcome should encourage future researchers to incorporate an element of self-efficacy in studies centering on obesity prevention. Self-efficacy can now be seen as the initial step to empower children to change their environment and evoke outward behavioral changes under their own autonomy.

Next steps for possible resolutions

School-based interventions continue to be an ideal environment to educate and promote healthful lifestyles considering the number of hours a child spends at school per week. Incorporating a nutrition curricula into the structure of elementary teaching plans, is one way to influence children's food choices. However, interventions that aim at altering a child's whole environment must also include the family. Although teachers may act as role models in educating and developing healthful dietary habits, this study in conjunction with other related studies, suggests that parental involvement is necessary to initiate and sustain an outward behavioral change (12).

Recommendations for future study

The health risks facing our nations' obese and overweight children are debilitating and lifelong. The results of this study confirm what has been previously reported, yet reveals what this means for future researchers. There appears to be a fine-line between parental involvement and parental over-control with regards to establishing and fostering a healthful dietary habit among children. Children must maintain a sense of autonomy with regards to eating freedoms in childhood in order to develop an appropriate relationship with healthful foods. Future researchers may consider the effect of early parental education on overall eating patterns beyond fruit and vegetable consumption.

Parents continue to be the most influential regarding a child's risk for obesity, in the area of supporting positive change (22). Because a significant amount of a child's learning about healthful dietary practices come directly from their parents, early parental education remains a focal point for impacting a child's overall health status. The results of this study, and other studies, indicate the need for future research on parental influence and control over environmental factors associated with obesity (7, 17). More investigation is needed to determine whether the type and depth of a parental education will evoke a greater impact on a child's outward behavioral change to foster desirable trends toward a more lean health status.

Self-reporting data is historically unreliable particularly with children; in an effort to strengthen the present findings, future researchers would benefit from collecting and comparing feeding observations at home using the Child Feeding Questionnaire (23). This questionnaire is a parental validated measure used to assess the parents' beliefs, attitudes, and practices' regarding their child's eating patterns. Assessing the parent's perception of their child's eating habits may give future researchers a clearer indication on the reality of their child's weight status.

There exists ample evidence that childhood obesity is a significant health concern (4). Evidence also indicates that in order to slow, stop, and reverse this trend more social ecological levels influencing a child's life must be investigated simultaneously. Therefore, individual, families, government agencies, community groups, educators, health care providers, registered dietitians, and other components of American society must get involved. Future research in this area should consider a triangulation approach to initiate and foster a healthful holistic anti-obesity approach. A whole environment approach might include foods being offered at school and at home simultaneously. Moreover, determining whether healthful individual food choices would be consumed, if available, needs to be ascertained. This type of assessment would best be determined through an observations study design. Education and assessment could also target specific food purchases practices to determine a change in food availability.

Considering the complexity of all the inter-related dimensions surrounding child-hood obesity, steps to increase awareness, improve nutrition education, initiate and foster healthful dietary practices, and create environments to increase physical activity must be seen as a shared community responsibility. Saturating a child's internal and external environment to evoke, and then sustain, a healthful lifestyle are essential to reverse childhood obesity trends in the United States. This shared responsibility will need to include the individual, their family, schools, the community, health professionals, registered dietitians, and policymakers, all coming together simultaneously and collectively with one targeted focus to increase the quality of life for our nation's children.

What does this paper add?

Based on the findings of this study, and consistent with a myriad of research conducted on nutritional education programming, only part of the overall hypothesis of this study can be supported. Nutrition knowledge and diet behaviors increase with nutrition education, as indicated in both groups. Thus, from a practical perspective those designing health curricula in schools should recognize that nutritional programs designed specifically for this age group can be effective in changing health habits and should be encouraged. However, results of the study do not support a change in physical activity behaviors in either group; thus, learning more about nutrition is unlikely to encourage more physical activity. In identifying the effect on self-efficacy, the child-plus-parental education group did show a significantly greater improvement over the child-only education group. Therefore, while nutritional programming for children-only can improve nutritional outcomes, this study recognizes the meaningful importance of including parents in this process by empowering children to make healthful nutritional choices.

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Chapter 10

POSTPARTUM DEPRESSION, INFANT TEMPERAMENT AND CHILDCARE STRESS

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The aim of this chapter was to explore postpartum depression (PPD) and the factors that can contribute to PPD, with an emphasis on child temperament and childcare stress. The study was conducted in Tirana and the sample includes 398 new mothers, from one month postpartum to one year post partum. Edinburgh Post Natal Depression Scale and the revised version of Beck Postpartum Depression Predictors Inventory (PDPI - R) were used in this study to evaluate women with PPD and factors contributing to PPD. Approximately 23% of women that used the Edinburg Postpartum Depression Scale were found to have PPD. When we correlated the relationship between postpartum depression, infant temperament and child care stress we found that postpartum depression and child temperament were correlated at a significant level.

INTRODUCTION

The postpartum period represents one of the most important life stages of women in which the accurate detection and treatment of psychological distress is required. Postpartum Depression (PPD) is a depression episode that begins within six months after birth and matches the criteria of DSM - IV for major depression without psychotic consequences (1). The prevalence of PPD is about 8-35% depending on the method used for evaluation (2). PPD occurs when there is an increase in demands on a new mother due to the child development.

Many different risk factors have been found to be at least moderately correlated with the presence of postpartum depression (3). These risk factors include a history of depression (preconception or prenatal), high stress level, high anxiety, and little or no social support. Although no single factor can be attributed to predicting postpartum depression, the

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combination of factors does seem very important in understanding both the short and long term outcomes as well as what strategies might be best for intervention.

Characteristic symptoms of PPD are similar to those of major depression including: sadness, despair, anxiety, compulsive thoughts, and appetite and sleep disturbances. A new mother with PPD may also have thoughts of harming herself and/or her infant (4). In addition to directly affecting a new mother's mental health, PPD can interfere with a mother's ability to recognize and respond to the needs of her infant, increasing the risk for delays in infant development and behavioral problems in childhood (5). Consequently, PPD is considered a major form of depression which requires treatment and identification of women who may be at an increased risk. Lack of diagnosis of PPD can affect the mother, her child, family members, and society through medical expense, social dysfunction, illness, and even death (6).

Postpartum depression and child characteristics

Various studies have reported that child related factors were associated with postpartum depression. Cutrona (7) reported that high levels of child care related stressors were associated with high levels of depressive symptomatology, while Hopkins, Campbell and Marcus (8) found that having a difficult baby, or a baby with neonatal complications, was associated with a diagnosis of postpartum depression.

Beck (9) studied two variables related to the infant; child temperament and childcare stress. She found that childcare stress and having an infant with a difficult temperament were moderately predictive of postpartum depressive symptomatology. It has been found that mothers suffering from postpartum depression give more negative descriptions of their children and report more behavioral problems in their infants, than control mothers (10). Therefore, the mothers' symptoms may be a source of bias in the reporting of infant characteristics.

The early postpartum period is a time of potential stress for the mother as she assumes increasing responsibility in the parenting role (11, 12). Symptoms of depressed mood emerge and occur more frequently during this stage (12). Since infant behavioral patterns also take shape early, it is possible that difficult temperament may either influence or be influenced by the maternal psychological state at this early postpartum stage (9, 13, 14).

In this study the relationship between infant temperament, child care stress and postpartum depression during the first year postpartum is assessed. Temperament refers to individual differences in an infant's expressions of arousal and emotion and describes infant self-regulation, reactivity, and modulation (15). Emerging temperamental difficulty may affect maternal interactions with the infant and may shape her future expectations of the child, potentially posing a stress upon the parent-infant relationship (16). Child care stress refers to the mother's perception of infant health problems, problems with baby feeding and problems related to baby sleep.

The main purpose of this study was to explore postpartum depression in Tirana, Albania and the predictors of PPD focusing on child temperament and child care stress. The results from this study will contribute to a better understanding of this problem, since there is a lack of studies regarding postpartum depression in Albania.

OUR STUDY

Edinburgh Postnatal Depression Scale (EPDS) was used for PPD screening. EPDS is one of the best standardized questionnaires used to assess PPD (17). Built with 10 self reported questions, EPDS has shown high levels of reliability and validity.

The revised version of Beck Postpartum Depression Predictors Inventory (PDPI- R) was used to elicit information on the risk factors related to PPD. The PDPI-R is an inventory that evaluates eight risk factors found to be significantly related to postpartum depression; child temperament and child care stress are two of them (18).

A sample of 398 women was part of this study. They were all woman one month to one year post partum who attended primary child health centers in Tirana. The study was conducted from July to December 2012 in primary child health centers of Tirana, Albania. The interview and filling out the questionnaire were conducted in private rooms, suitable for the participants and the researcher, after the informed consent was taken from participants.

The data was analyzed using the Statistical Package for the Social Sciences (SPSS Version 16.0 for Windows). The data collected through the questionnaire was subject to descriptive statistics.

FINDINGS

Most of the interviewed mothers were 21-30 years old (60%) and 99% married. 56% had their first child and 48% had a university degree. Twenty-seven percent (n = 109) reported that the pregnancy was unplanned and only 7% indicated the pregnancy was unwanted (n = 29). The majority of the females had vaginal deliveries (62%). After delivery 17% of the mothers reported health complications for themselves and 8.3% reported complications for their new born.

Prevalence of postpartum depression

Table 1 indicates that approximately 23% of sampled women had results indicating PPD. This data was collected using the EPDS. In this study EPDS was found to be highly reliable (10 items; α = .84). However, a clinical diagnosis is necessary for a clearer assessment of PPD.

Table 1. Postpartum depression

	Frequency	Percent	Valid Percent	Cumulative Percent
No Depression	305	76,6	76,6	76,6
Depression	93	23,4	23,4	100,0
Total	398	100,0	100,0	

Table 2. Postpartum depression and temperament

Correlations			
		PPD	Temperament
PPD	Pearson Correlation	1	.296**
	Sig. (2-tailed)		.000
	N	398	398
Temperament	Pearson Correlation	.296**	1
	Sig. (2-tailed)	.000	
	N	398	398

**Correlation is significant at the 0.01 level (2-tailed).

Table 3. Postpartum depression and child care stress

Correlations			
		DPP	Childcare stress
DPP	Pearson Correlation	1	.259**
	Sig. (2-tailed)		.000
	N	398	398
Child care stress	Pearson Correlation	.259**	1
	Sig. (2-tailed)	.000	
	N	398	398

**Correlation is significant at the 0.01 level (2-tailed).

Postpartum depression and child temperament

Pearson correlation is used to evaluate the relationship between postpartum depression and child temperament. As shown in Table 2, postpartum depression and child temperament were weakly to moderately correlated at a significant level; r (398) = .30, P < .01.

Postpartum depression and child care stress

Pearson correlation was used to evaluate the relationship between Postpartum Depression and child care stress. As shown in Table2, postpartum depression and child care stress were weakly correlated at a significant level; r (398) = .26, P < .01.

DISCUSSION

Having a child is a period of biological, psychological, and social change and these changes can contribute to personal growth and happiness, but they may also predispose the female to emotional distress. This study offers important information about postpartum depression (PPD) and child characteristics.

According to Milgrom et al. (2) the prevalence of PPD is about 8-35% and in our present study we found 23% of new mothers had signs of PPD. Results indicate a high prevalence of postpartum depression in Tirana. The lack of studies related to PPD in Albania makes it difficult to have a clear representation of the problem, but it also indicates the desperate need for these studies. It should be noted that this is only a prediction of PPD and that a clinical diagnosis is needed for a clearer assessment.

Hopkins, Campbell and Marcus (8) found that having a difficult baby or a baby with neonatal complications was associated with a diagnosis of postpartum depression. Consistent with the findings from prior studies, the results suggest that depressed mothers have poorer ratings of their infant temperament than non-depressed mothers. Interventions are needed because long-term depressive symptoms and poorer perception of infant temperament have the potential to affect infant and child cognitive development (9).

Child care stress which refers to the mother's perception of infant health problems, problems with baby feeding and problems related to baby sleep, during this study reflected a weak positive relationship with PPD. Infant health problems are stressful for new mothers but they not always result in PPD. Sometimes mothers gain strength from these problems so that they can better aid their new born. Child care stress during the first months postpartum is also often related to mothers’ social support system.

This study used PPDI-R, a 3-item measure of infant temperament and a 3-item measure of child care stress. It is possible that this brief assessment of mothers’ perceptions is not the best method to fully measure the infant temperament.

The current study results make us believe that the provision of adequate postpartum care is crucial in the identification of emotional distress. Considering the high prevalence of PPD during the mothers' postpartum period, these kinds of studies are crucial for early identification of symptoms and early treatment of mothers, children, and families.

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Chapter 11

HIP PAIN IN A CHILD

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Hip pain is a relatively common complaint in children, the etiology of which can range from a benign to a serious condition. The vast majority of children with joint and extremity pain do not have serious disease. This case is unique, because when the patient presented to our facility, she had a presumptive diagnosis of a treatable condition made at another facility. Further evaluation led to the diagnosis of neuroblastoma. This case is presented because it is an example of how hip pain can be an atypical presentation of a devastating disease.

INTRODUCTION

Hip pain in children and adolescents can be due to multiple causes, mostly benign; however, it is important to recognize certain conditions that can have serious consequences for the patient. We present a case report to illustrate the importance of vigilance and a high index of suspicion when evaluating a child who presents with hip pain.

A 5 year old Caucasian female patient was transferred to the Children's hospital for further evaluation of left hip pain and anemia. A presumptive diagnosis of left slipped capital femoral epiphysis was made based on initial clinical and radiological findings at the referring institution. Predominant symptoms included left hip pain for two weeks, inability to bear weight on the left leg, and fever. Prior to this presentation, the patient had multiple visits to urgent care centers for musculoskeletal complaints including neck pain, chest pain, back pain, and abdominal pain. These symptoms were associated with a weight loss of about three kg in the preceding six months. On physical examination, vital signs were stable, her left hip was

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kept in the flexed position and she refused to move the left leg due to pain. Patient had muscle atrophy of the left thigh and lower leg, and also had leg length discrepancy with the left leg measuring approximately 1 cm shorter than the right leg. No abdominal mass was palpable. An X-ray of the hip showed sclerotic changes on the left proximal femur (see figures 1 and 2); ultrasound of the left hip joint demonstrated an effusion.

A peripheral blood smear was significant for a normocytic, normochromic anemia, no blasts were seen. A magnetic resonance imaging of the left femur and hip showed extensive marrow signal abnormalities (see figure 3).

Nuclear medicine bone scan showed multi-focal bone lesions throughout the skeleton. Bone marrow biopsy showed stage IV neuroblastoma. Axial imaging demonstrated a left adrenal tumor which was subsequently resected. She was started on appropriate chemotherapy.

DISCUSSION

Most children, who present with hip pain, are initially diagnosed with benign conditions such as transient synovitis, reactive arthritis, or soft tissue injury (1). Others may present with acute conditions such as a fracture, septic arthritis, or osteomyelitis (1). A small number will present with conditions that have a good prognosis with treatment, such as slipped capital femoral epiphysis (SCFE), juvenile idiopathic arthritis, Lyme disease, or rheumatic fever. A very small percentage of those will be diagnosed with conditions such as leukemia, bone tumors, or metastatic malignancies (2). Our patient's initial diagnosis of SCFE was not consistent with the clinical picture. SCFE usually presents in obese children who may have a history of trauma (1), neither of which were true for this patient. With the history of systemic symptoms and migratory pains, juvenile idiopathic arthritis was also high on the differential.

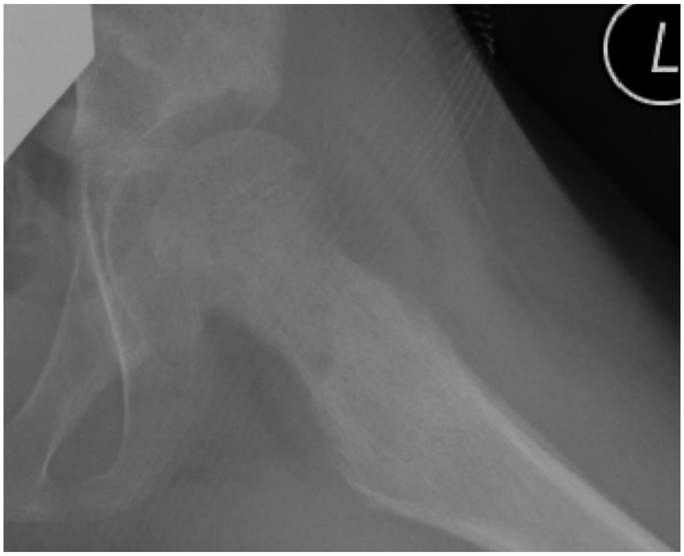

Figure 1. X-ray of left hip showing sclerotic changes.

Figure 2. X ray of pelvis showing sclerotic changes of the left proximal femur.

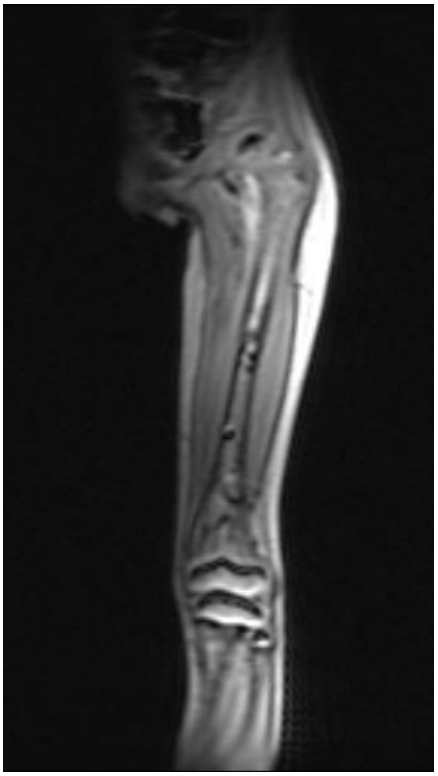

Figure 3. Magnetic resonance imaging of left hip and femur showing extensive bone marrow signal abnomormalities.

The initial pelvis and left hip radiograph showed sclerotic change of the left femur with new periosteal bone. This was more consistent with osteomyelitis or a benign tumor. Malignant tumors usually have ill-defined margins, periosteal reaction, or soft tissue calcification (2). Also, rapidly enlarging lesions on radiographs are usually suggestive of malignancy, but benign lesions such as aneurysmal bone cysts may present similarly (2).

After evaluation by orthopedic surgery, pediatric rheumatology, and further imaging, a bone marrow biopsy was done. Several studies have stated that a bone marrow biopsy has a higher yield of detection of metastatic neuroblastoma compared to a bone marrow aspirate (3-

8). Prior to the bone marrow biopsy, leukemia was high on the differential. Generalized bone pain is the presenting symptom in about 50% of newly diagnosed children with acute lymphoblastic leukemia, making it the most common cancer which presents with bone pain (2). Although, with the bone scan showing multifocal bone lesions, a metastatic process was likely in this patient, narrowing our differential diagnosis down to metastatic Ewing sarcoma, rhabdomyosarcoma, or neuroblastoma; with Ewing sarcoma more common in children younger than 10 years of age (2). Patient was ultimately diagnosed with stage IV neuroblastoma, primary adrenal tumor with extensive metastasis to the bone and bone marrow.

CONCLUSION

Advanced stage neuroblastoma has a high mortality rate for children over the age of 1 year; most infants with disseminated disease have a favorable outcome following intervention (4). Despite the advances in therapy, the survival from advanced disease in neuroblastoma remains poor (5). Multiple salvage regimens prolong survival, but the long term disease free survival after recurrent disease remains small (5). This case had several factors which led to a delay in diagnosis. The presentation was atypical for neuroblastoma, with an abdominal mass being the most common presentation. This case reminds us of the importance of an established primary care provider and the careful follow-up when complaints do not resolve as expected.

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Chapter 12

EFFECTIVENESS OF WII EXERGAMES ON CHILDREN'S ENJOYMENT, ENGAGEMENT, AND EXERTION IN PHYSICAL ACTIVITY

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Although previous studies have noted that exergames increase physical activity and physical exertion compared to sedentary videogames, no empirical studies have compared the differences between types of exergames in relation to physical exertion and perceived enjoyment. This pilot study investigated children and adolescents' perceived enjoyment, engagement, and overall exertion while playing Wii exergames through an experimental design. A correlation was found between children's reported level of exertion and perceived enjoyment. The findings revealed that exergames requiring more physical exertion (e.g., cardio boxing exergame) were perceived less enjoyable than those requiring only minimum amounts of physical activity (e.g., obstacle course exergame). In addition, children's self-reported level of engagement with each game was not dependent upon the degree of difficulty of the game. The current study representing data from a pilot study served as a foundation for a much larger study that would target special population and children already battling overweight and obesity. The theoretical and practical implication was discussed.

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INTRODUCTION

Obesity and overweight populations have reached almost epidemic proportions in the United States. Physical inactivity has been noted as one of the most serious health concerns facing the United States. Childhood obesity specifically, has tripled in the past 30 years, and for children aged 6 through 11 years, obesity rates have increased from 6.5% to 19.6% in 2008 (1). Research has shown that when obesity is present in childhood, it often persists into adulthood (2).

One solution to this problem is increasing opportunities for physical activity. Physical activity has been noted as being an important tool for the prevention of obesity and other chronic diseases, such as heart disease, hypertension, and type II diabetes (3). However, despite the health benefits of physical activity, only 38% of American adolescents engage in organized physical activity outside of school hours (4). A 2009 survey noted that fewer than 20% of high school students engaged in physical activity requirements at the recommended level: 60 minutes per day (5). Given recent reports about physical education time being decreased in elementary and middle schools to focus more attention on academics, one has to wonder if children are getting much opportunity at all to participant in physical activity, exercise, or sport.

It should be noted that one of the primary factors that contributes to sedentary lifestyle is the amount of time spent in front of a digital screen. A recent survey by Nielsen found that adolescents between the ages of 6 and 11 years spend more than 28 viewing hours per week watching television and 2.5 hours playing video games (6). The research further reported that school-age children on average spend three hours a day watching television (6). According to a recent survey by the Pew Foundation, adolescents age 8 to 11 spend over 7 hours a day using media (e.g., television, music, video, video games etc.). This time spent in mainly sedentary activities significantly outweighs the time available for activities that are less passive and sedentary. Many scholars have found a positive correlation between heavy television viewing and obesity (7, 8). In considering the overall screen time adolescents accumulate on a daily basis, researchers must consider the widespread usage of media in areas of the home other than in family rooms.

While many video games are sedentary in nature, video game manufacturers introduced newer gaming devices (e.g., Wii, Kinect) that offer players opportunities to be more active through game play. A substantial body of research suggests that video game usage has a negative effect on players with regard to aggression, weight problems, and social isolation, but this body of research has not included exergames as a game category for analysis. Exergame playing may be beneficial for children and audiences by providing enjoyment while increasing energy expenditure. Nevertheless, the empirical investigation of the positive effects of exergames is scant if non-existent in the literature. Therefore, the current study seeks to bridge the gap by examining the relationship between exergame usage and perceived enjoyment and exertion in a population of children at-risk for obesity or overweight. Specifically, the present study investigates the effects of a series of Wii games varying by energy expenditure levels on children’s enjoyment, engagement, and exertion. The current research represents data from a pilot study serving as a foundation for a much larger study that will target special populations and children already battling overweight and obesity. It also tests a health literacy and physical activity intervention program that could be implemented in schools, after-school centers, or at home to help children at-risk or overweight become more physically active. Thus, the researchers test the instructional models within each exercise game to see if child participants were able to engage in the exergames as much as they do using traditional but inactive video games.

LITERATURE REVIEW

The prevalence of overweight and obesity among American children and adolescents drastically increased since the 1970s, and no race, ethnicity or gender emerged unaffected (4). Though efforts to combat childhood obesity helped lessen the trend in recent years, weight issues among children and adolescents remain a top health concern for the nation (5). Weight problems could carry serious physical and mental health consequences. Overweight and obese children faced greater risk of developing illnesses such as diabetes and high blood pressure. (9) Furthermore, children and adolescents who became victims of anti-fat bias and weight stigmatization may develop poor body image, low self-esteem, depression, and eating disorders (10, 11). A variety of individual and social factors influenced whether a child will become overweight or obese, and one of these factors includes media exposure.

While television viewing displaces chances for more stringent exercise, it cannot be said that children who watch large quantities of television are necessarily inactive. Several studies have documented correlations between heavy television viewing and obesity in children. The question, however, remains, does an overweight child choose to spend more time with television because he or she is uncomfortable participating in physical activities or does the media use drive the sedentary behavior, which may lead to a child becoming overweight or obese? For example, data collected during the National Health and Nutritional Examination Survey between 1988 and 1994 showed that obesity was least prevalent among children who watched an hour or less of television a day. The highest prevalence was documented among children who watched four or more hours of television a day (12). A longitudinal study examining similar variables found that participants who watched the most television during childhood showed the largest gain in body fat between preschool and early adolescence (13). Obesity, in turn, may directly negatively affect the overall level of daily exercise. Studies have found that obese children were less likely to regularly exercise, less likely to express confidence in their ability to perform well in physical activities, and less likely to take part in organizations focused on physical activities such as team sports (14). Researchers recommended that any intervention program targeting childhood obesity taught children about the importance of physical activity, and showed overweight and obese children that they, too, could succeed (14). Among other objectives, the intervention in the present study sought to raise children's self-efficacy for physical activity.

HEALTH AND MEDIA LITERACY INTERVENTIONS

A challenge in educating children about the dangers of obesity is getting children to understand the link between present behavior and future consequences. If a child doesn't have the cognitive capacity to understand obesity and make links between current eating and exercise behavior and long-term health, that child may be at a higher risk for becoming overweight or obese. The US Department of Health and Human Services defines health literacy as the “degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness” (15). Health literacy is crucial in addressing childhood obesity. Yet, the population at the greatest risk of becoming overweight or obese is least likely to recognize risk factors associated with weight gain. Children may not equate food and exercise with their short and long-term health because they may not understand the direct relationship between weight and general health. Thus, health literacy is especially relevant for young children and children who may be at a disadvantage in knowledge, comprehension, and awareness as it relates to health.

Health education is not taught in the context of media, yet children receive many messages about food and health via the media. The problem is that these messages are often negative or harmful. Therefore, a necessary step in health education is to teach children to become more critical consumers of the media. Interventions may also help children see the potential of using the media for positive ends.

EXERGAMES AS A TOOL TO PROMOTE PHYSICAL ACTIVITY

Given the fact that childhood obesity is rapidly increasing in the U.S., the development of health interventions with novel features that engage young children is essential. Therefore, a new generation of exercise video games (exergames) has the potential to both motivate and engage children to participate in physical activities. Although playing home video games has been traditionally a sedentary activity, exergames including the Wii (Nintendo), Playstation Move (Sony), and the Kinect (Microsoft) may offer opportunities to change the ways that children and adolescents interact with videogames. These game consoles require individuals to perform physical movements in order to control and complete game objectives. Specifically, the Nintendo Wii has been categorized as an exergame technology that requires dynamic physical movement from its participants. The innovativeness of these next generation consoles can be derived in the form of wireless controllers that contain motion sensors. Nintendo has recognized the potential of the Wii as an exercise tool and has released a series of fitness-based games (e.g., Wii Fit, Wii Sports, Wii Dance etc.) that are manipulated through a combination of the Wii remote and the Wii Fit Balance Board. These tools are meant to be extensions of the main Wii console and allow for the collection of additional player information such as Body Mass Index (BMI).

To date, only a few studies have examined the potential of new generation video game consoles in increasing active behavior. For example, Graves, Stratton, Ridgers, and Cable (16) investigated the effect of Wii games (e.g., Nintendo Wii bowling, tennis, and boxing) on overall energy expenditure. Results from the study demonstrated that exergames elicited 51% higher energy expenditure than comparative sedentary games, indicating that playing active Wii games used more energy than playing sedentary video games. A more recent study conducted by White, Kilding, and Schofield (17) reported similar findings. The authors compared active video game playing (Nintendo Wii Bowling, Boxing, Tennis, Skiing and

Step Aerobics), sedentary activities, and physical activities, with the children's heart rate, oxygen uptake and energy expenditure being measured. The authors found that playing active video games elicited higher energy expenditure than sedentary activities. In addition, children rated the active video games as the most enjoyable among the three forms of activities. Prior research has found that exergames were enjoyable and engaging, regardless of the required level of physical activity (18). For example, in Finkelstein, Nickel, Lipps, Barnes, Wartell, and Suma's (19) study, people who finished an exergame stated: "It didn't really feel like exercise — I wasn't focused on my heart rate or trying to push myself. I just played the game. It wasn't until afterwards it had felt like I had done any exercise" (p. 88). Other than solely comparing exergames with traditional video games in terms of energy expenditure, Song, Peng, and Lee (20) included psychological factors in examining the positive effect of exergames. The authors found that individuals with low body image dissatisfaction rated the exergame as more enjoyable and subsequently reported a more positive mood after exercise when the video game characters resembled their real-life appearance.

The literature reviewed above indicated that exergames were not only enjoyable, but also valuable tools to promote physical activity. With record numbers of sedentary screen-time, this body of research has shown that exergames could be used in motivating children to be more active in an easy and fun way (21).

THEORETICAL FRAMEWORK: CULTIVATION THEORY

Previous research has demonstrated that television viewing may be negatively related to children's food preferences, food intake, nutritional knowledge, and physical activity because it might not only shape what they viewed to be healthy and good for them, but it might also shape their preferences for specific foods and how much food they consumed while watching television or viewing might influence — indirectly or directly — physical activity. Signorielli and Staples (22) explained this relationship between television viewing and behavior as it related to health via cultivation theory (23) and suggested that it was the repeated viewing over time of similar content that contributed to an individual's beliefs about social reality. Cultivation theory has been applied in several contexts with regard to the way media, especially television, contributed to distorted beliefs and perceptions about social reality as it related to body image (24). Hesse-Biber and colleagues (24) examined four social psychological theories, including cultivation theory, to better understand how women and girls were exposed to and affected by the media as it related to body image distortion and the "cult of thinness." They argued that these theories offer a "nexus of influence and provide important clues to our understanding of the pervasive influence and impact of these industries on the development of eating disorders in women" (p. 208). Levine and Smolak (25) expanded on this by stating that the "constant repetition of certain forms and themes (values) as well as the constant omission of certain types of people, actions, and stories, powerfully influence and homogenizes viewers' conceptions of social reality" (p. 250).

While the act of viewing television has often resulted in more negative outcomes such as those listed above, some research indicates media or television can be used to produce more pro-social outcomes, possibly even increasing physical activity. Obesity represents one of the two key areas where the influence of the medium may go beyond the level of being correlational or contributory and rises to the level of cause and effect (26). Given the controversial nature of this statement, researchers across disciplines are trying to determine if television viewing causes obesity or if obese children tend to be more sedentary and watch more television (26, p. 391). While it was not the objective of the present study to examine the specific relationship between television viewing and obesity or overweight, it was an objective to determine if new media technologies such as the Wii could be used as a component of helping at-risk children engage in an activity that would help them become healthier.

We argue here that one key aspect of any media literacy program is one that uses context. In order for children to understand messages about food, nutrition, or exercise, they need to be given examples of those mediated messages in a context they are familiar with. Along these lines, children need context in order to understand why the information viewed is relevant. For example, children may be exposed to advertisements for Fruit Loops cereal or a McDonald's happy meal. These advertisements need to not only be seen in the context in which they are viewed but in the context of the way they might interact or engage with the items being advertised. If specific attention is paid to the individual factors that might aid in a child's ability to learn and might aid in a child's motivation to learn, it is possible positive changes will result. As it relates to physical activity, if children are shown ways they can become physically active in a familiar context — using a Wii gaming device, using a gaming device at home, the negative connotation often associated with exercise could be turned into something more positive.

OUR STUDY

Although previous studies have noted that exergames increased physical activity (27) and physical exertion (16) compared to sedentary videogames, no empirical studies have compared the differences between types of exergames in relation to using exergames to motivate children to engage in physical activities. In particular, the literature is limited in examining the interaction between several key variables related to the effectiveness of exergames such as enjoyment, engagement, and exertion in promoting the effectiveness of exergames. Do children enjoy playing exergames? If so, is this enjoyment related to different types of exergames? These questions have yet to be answered. Finding the answers is essential not only for game designers but also for health practitioners and researchers who want to use exergames to promote physical activity and pro-healthy behaviors. Therefore, the variables that are investigated in this pilot study are essential to foster our understanding of using exergames as a tool to engage younger population into physical activity.

In this pilot study, we are interested in whether the most enjoyable games lead to the greatest amount of exertion. Previous studies have demonstrated that variance in exergames is related to the amount of physical exertion, but no comparative studies have examined this relationship. Because video game design and game objectives vary considerably depending on the goals and physical motions required to meet the game's achievements, it is reasonable to assume that attitudes toward exergames will vary according to personal attitudes, level of experience with gaming, and level of experience with exercise. The purpose of the present study is to evaluate the perceived enjoyment, perceived engagement, and overall exertion of children and adolescents while playing exergames. Therefore, the following hypothesis and research questions are proposed:

- H1: Participants' self-reported level of enjoyment will be dependent upon the degree of physical intensity of the game.
- H2: Participants' self-reported level of engagement with each game will be dependent on the degree of physical intensity of the game.
- H3: Participants' self-reported level of exertion will depend on the degree of physical intensity of the game.
- RQ1: Is there a correlation between participants' reported level of exertion and perceived enjoyment?

The goal of the present study was to conduct a pilot test of children and adolescents to determine if the general premise of the study would be suitable for a larger-scale project. The present project also served as a pilot study for a similar study using psychophysiological measures. Therefore, a convenience sample of 19 participants (10 boys, 9 girls) was recruited from local elementary schools. Their ages ranged from 7 to 14 (M = 9.6, SD = 1.9). Participants were recruited through informational sessions at each school. The study was approved by the Institutional Review Board (IRB) at the University, and participants gave informed (parental) consent and assent respectively. No prior experience with the Wii was necessary for participation.

Stimuli

To examine the effects of exergames on behavioral intentions to continue exercise at home and to ensure that effects were not limited to one particular game, four different exergames were employed. They were (a) obstacle course (from Wii Fit Plus), (b) canoeing (from Wii Dance), (c) sports medley (from EA Sports Active), (d) cardio boxing (from Gold's Gym Dance Workout). The four games varied by their levels of physical intensity. The "obstacle course" was an exergame that required the player to avoid obstacles to clear a series of four levels of increasing difficulty. The "canoeing" game required players to paddle down a waterway, avoid obstacles, and finish the course before the timer ran out. The "sports medley" game was a series of three different sports: boxing, running, and pitching. The "cardio boxing" game required the player to mimic the movements of onscreen characters that perform a repetitive series of cardio boxing motions. We purposely selected these four games according to their level of physical intensity, with the obstacle course game requiring the least physical activity and the cardio boxing game requiring the most physical activity.

Participants played the games on a Nintendo Wii game system (Nintendo Co Ltd, Minamiku Kyoto, Japan) with a 50-inch Sony high-definition television in a child media lab in a large southeastern U.S. university. The participants played the Wii games using a wireless remote control with motion sensors. Two of the games (e.g., obstacle course and canoeing) required the Wii Fit Board. The Wii Fit Board was a wireless accessory that activates when players stand and perform movement on the board.

Procedures

Data collection from each participant was performed in one session. Before data collection began, the participants were familiarized with the environment and given an overview of the activities. To establish familiarity with the Wii game system and controllers, all participants received 10 minutes of practice with a Wii exergame that was not included in the study. Participants then played each of the four games for five minutes. Participants were given basic instructions for each game and were then allowed to follow the onscreen instructions specific to each game. Following each game, each participant completed an online questionnaire measuring enjoyment, engagement, and perceived exertion. Researchers stayed in the room to monitor the participants and ensure their safety. Assistance was available if participants had questions regarding the onscreen instructions or had difficulty with the controller.

Dependent variables

The dependent measures were a set of enjoyment, engagement, and exertion scales that were measured via a computer-based questionnaire. Participants completed the questionnaire immediately following each game.

Enjoyment. Enjoyment was measured with five items on a 3-point scale (1 = disagree, 3= agree). The 5-items asked how good, exciting, and inspiring participants perceived the gaming experience. Example statements included “This game was exciting” and “This game made me feel good.” The Cronbach’s alpha for this scale was α = .81.

Engagement. Engagement was measured with three items on a 3-point scale (1 = disagree, 3 = agree) developed by Lessiter, Freeman, Keogh, Davidoff (28). The scale was employed to measure the extent to which the participants felt that they were engaged in the Wii game. Example statements included, “I lost the track of time” and “I had a sense that I had returned from a journey.” The Cronbach’s alpha for this set of scales was α = .62.

Exertion. Participants rated their exertion with a 12-item 3-point scale (1 = disagree, 3 = agree) designed to measure the perceived level of their exertion during the game. Example statements included, “Working out with the Wii game was like working out in P.E.” and “The Wii fitness game gave me good instruction on how to work out.” Cronbach’s alpha for this scale was α =.86.

Statistical Analysis

Both descriptive and inferential statics were conducted on each dependent variable. Normality was assessed through skewness and kurtosis. The exertion scale was assessed with a repeated measures analysis of variance (ANOVA) and paired-contrasts. Subsequently, Friedman’s tests and paired-contrasts were conducted for the enjoyment and engagement scales due to non-normal distribution of the data.

FINDINGS

H_1 predicted that children's self-reported enjoyment would be dependent upon the degree of physical intensity of the game. To test H_1, a Friedman's chi-square test was conducted. H1 was supported as a significant difference was found in the rankings of enjoyment across the four games, Chi-square (3, N = 19) = 50.10, p < .001, W = .88. Specifically, participants enjoyed the low physical intensity, "obstacle course" game the most (M = 2.58, SE = .42), followed by "Canoeing" (M = 2.42, SE = .42), whereas they enjoyed the high physical intensity, "cardio boxing" game the least (M= 1.42, SE = .42). The mean ranks and the standard errors for the four exergames are presented in Table 1.

H_2 predicted that children's self-reported engagement with each game would be dependent on the degree of physical intensity of the game. To examine this hypothesis, a Friedman's chi-square test was conducted. H_2 was not supported as no significant effects were found between engagement and the physical intensity of the game.

H_3 predicted that children's self-reported levels of exertion would depend on the type of game. A repeated measure ANOVA was conducted. The results demonstrate that there was a significant difference among the four games in terms of reported exertion, F(1,18) = 7.68, p < .001. The F test was adjusted by the Greenhouse-Geisser correction because the Mauchley's sphericity test was significant. Children who played the "obstacle course" exergame reported the lowest exertion scores (M = 1.91, SD = .13). In contrast, children who played the "sports medley" exergame reported the highest exertion scores (M = 2.46, SD = .13). The other two exergames, canoeing and cardio boxing, elicited moderate exertion scores (M = 2.30, SD = .14) and (M = 2.18, SD = .16) respectively (see Table 2).

Table 1. Ranked means and standard errors for enjoyment of the four exergames

Exergame	Mean	Standard Error
Obstacle Course	2.58	.42
Canoeing	2.42	.42
Sports Medley	1.58	.42
Cardio Boxing	1.42	.42

Table 2. Ranked means and standard deviation for exertion of the four exergames

Exergame	Mean	Standard Error
Obstacle Course	1.91	.13
Canoeing	2.30	.14
Sports Medley	2.46	.13
Cardio Boxing	2.18	.16

RQ1 asked whether a correlation existed between children's reported level of exertion and perceived enjoyment. This research question was tested through the computation of the correlation between exertion and enjoyment. The two variables were positively correlated among all the exergames, "obstacle course" (Spearman rs = .73, n = 19, p < .001 two-tailed), "canoeing" (Spearman rs = .82, n = 19, p < .001 two-tailed), "sports medley" (Spearman rs = .61, n = 19, p < .001 two-tailed), and "cardio boxing" (Spearman rs = .94, n = 19, p < .001

two-tailed). There was a moderate to strong correlation between children’s reported level of exertion and perceived enjoyment across games. The strongest positive correlation between level of exertion and enjoyment was found for the “cardio boxing” game.

Table 3. The correlation of enjoyment and exertion across four exergames

Exergame	Spearman r_s	N
Obstacle Course	.73***	19
Canoeing	.82***	19
Sports Medley	.61***	19
Cardio Boxing	.94***	19

Note: *** indicates p < .001.

Qualitative feedback

We also asked participants to express their overall feelings regarding the game playing experience in this pilot study. Considering that the participants were young children with limited writing capabilities, oral communication was employed. In general, we received positive feedback in terms of enjoyment and engagement of the exergames. A large portion of the participants thought the games were fun and expressed their intention to play again in the future. When they were asked whether they were engaged in the exercise, over half of the participants provided positive answers. Furthermore, over half of the participants indicated that exercising with a Wii exergame was very similar to working-out at school. Also, one participant stated that “Running with a Mii is more fun than running on the play ground.” It is interesting to note that participants’ qualitative reactions reflected the findings of quantitative measures.

The negative feedback that the authors received was mainly concerned with frustration elicited by the exergames. For example, the Wii dance exergame was fast paced and required complex movements. Participants who had difficultly keeping rhythm or performing the required movements expressed notable frustration. One participant even stopped playing due to the fast pace of the exergame. Other factors, such as game design, may contribute to the amount of exertion required. For example, participants reported a high degree of frustration when performing the movements required by the “canoeing” game. Observations from the study revealed that participants were expending greater amounts of energy attempting to play the game than it was necessary to complete the game. This observation holds significant practical value for the exergame industry: if players cannot perform the intended movements required by the exergame, they may expend a greater amount of unnecessary energy and therefore may be quickly frustrated and stop playing the game.

Based on our observations, we found that participants, regardless of minor frustrations, enjoyed playing most of the exergames. In addition, the amount of exertion was negatively correlated with the difficulty of the exergames. If a game was perceived as too frustrating, participants were more likely to stop performing the required movements. We also observed that other psychological factors, such as frustration and embarrassment might contribute to the overall enjoyment and engagement.

DISCUSSION

A number of individual and social factors contribute to whether a child becomes overweight or obese, including the variables addressed in the present study: children's interaction with physical activity and exergames. The main goal of this pilot study is to test key variables that may contribute to the use of exergames to promote physical activity among children. Through an experimental design, the present study investigates the effects of physical intensity of a game on children's enjoyment, engagement, and exertion. The results reveal several interesting findings that require further discussion.

Exergames have been documented as a promising tool to promote physical activity among both adults and children (20). Little research has been done to investigate the effectiveness of exergames to promote physical activity as opposed to field exercise. Researchers of exergames have been curious about the effectiveness of these games as real exercise in terms of exertion. In this particular study, we are interested in whether children who play exergames are able to obtain enough physical exertion while gaining psychological enjoyment. The primary finding of this study is the inverse relationship between enjoyment and exertion. Exergames requiring more physical exertion are perceived as eliciting less enjoyment than those requiring only minimum amounts of physical activity. For example, participants rated the obstacle course exergame as the most enjoyable, whereas it required the least amount of physical activity. Pervious literature has noted that perceived enjoyment is a critical factor in determining the motivation to continue physical exercise or activities (29). Children and adolescents are more apt to participate in physical exercise if they find it more enjoyable. Since exergames require a certain degree of physical activity, it is possible that enjoyment will be a factor in motivating children to play exergames. Our findings offer support for this hypothesis in a gaming environment and highlight the importance of enjoyment as a critical variable in using exergames as effective health interventions.

This finding, although with a limited sample size, has significant implications for health practitioners and parents who are seeking alternative activities to physical activities among children. Although health practitioner and researchers have proposed many structured, exercise-focused interventions in the past, the mixed findings of these solutions may be attributed to one simple reason, that is children may think traditional activities such as running and catching are boring while watching TV and playing video games are fun. The findings from this study suggest that "playing video games while having exercise is fun." Unlike previous exercise interventions, exergames have the potential to provide novel and fun ways to motivate children to engage in physical activities (20). Therefore, health interventions with novel technology and unique programs such as exergames should be developed and encouraged. The exergames tested in this study can be incorporated in health literacy and physical activity intervention programs that can be implemented in schools and after-school centers to help children at-risk or overweight become more physically active.

Findings from this study also provide implications for game designers who attempt to make the game enjoyable and engaging. The differences in enjoyment between the four exergames suggest that other factors, beyond level of exertion, such as camera angle and interactivity, may play a critical role in perceived enjoyment. For example, the "obstacle course" exergame featured a moving camera that progressed with the character, while the cardio boxing featured a static camera angle that mirrored the Mii characters. It is possible that the moving camera angle increased presence and therefore elicited a greater sense of enjoyment than the stationary camera angles in exergames. Other elements such as interactivity may also influence both enjoyment and engagement. The two games that were rated the highest in enjoyment, “obstacle course” and “canoeing” featured more interactive elements than the “sports medley” and “cardio boxing.” In the “obstacle course” exergame, the player encountered numerous moving elements (swinging objects, moving floors, rolling logs) compared to the “sports medley” that featured static elements (punching bags, stacks of bottles) or the “cardio boxing” (characters moving). Therefore, it is possible that exergames featuring a higher number of interactive elements increased both enjoyment and engagement. Little research has examined what media characteristics of exergames may increase enjoyment, engagement, and exertion. Future studies will need to examine the differences in game designs of exergames to determine what design elements influence theses variables.

This pilot study also contributes to the limited body of literature in the exergame domain by broadening the scope to a different group. The scales for measuring enjoyment, engagement, and exertion were adapted from existing measurements that have been applied to adults. Surprisingly, we found that the reliability of these scales were not particularly low even though the tested participants were children between 7 and 14 years old. Although we made some necessary changes such as modifying 7- point scales into 3- point ones, this finding fosters confidence in using enjoyment, engagement, and exertion measurement scales to children.

The individual, social and psychological factors that contribute to weight gain and obesity are certainly relevant in gaining better understanding of how children form and maintain beliefs about their own growth and development. Accordingly, in measuring a child’s current physical activity level and his or her attitudes about exercise, it is important to examine media as one driving component in the development of knowledge, beliefs, and attitudes about those issues. The media are often blamed for increases in childhood obesity, but beyond articulating that children spend too much time with the media, very little is known about how specific content may influence children’s thoughts and decisions about physical exercise. Participants in the present study were asked questions about their daily media use and asked about their daily physical activity. Having that information will allow us to work the information into the health literacy and physical activity intervention program. For example, when children were asked about the amount of time they spent playing games like Wii or DS, we then asked them to consider what other activities they could be doing instead. Children may hear from parents and educators that they spend too much time watching television or playing games, but they might not be told why that time spent with media is a bad thing. If they are taught that exergames can be one way they can become more physically active, they can then use that information to improve their own health. Given their limited cognitive abilities and their developmental skills, it seems crucial that information presented to children needs proper contextualization.

In general, this exploratory study reveals that enjoyment, engagement, and exertion are variables that are fundamental in examining the use of exergames to increase physical activity in children and adolescents. However, this study is not without limitations. The small sample size required non-parametric methods and subsequently limits the generalizability of the findings of this study to the greater population. These limitations are, however, frequently encountered in exploratory studies and do not belittle the findings. Future research should build on the findings of the present study with hope that exergames offer a practical supplement to traditional exercise in hopes of combating the childhood obesity epidemic that faces the United States.

While findings from the present study suggest the physical activity program, including Wii exergames, can be used effectively to engage children in enjoyable physical activities that increase overall heart rate, there are some limitations of this pilot study that need to be addressed. First, in terms of using exergames like the Wii to encourage physical activity, it should be noted that this pilot study took place in an artificial environment (lab setting) rather than at home. It is possible our findings would be stronger if we conducted an ethnographic home study where we could monitor the participants in a familiar setting. Furthermore, it is argued that a closer examination of a child's social and home environment — specifically the weight of family members, the attitudes and emphasis of weight at home — is needed along with measures that examine participants' discussion of weight among peers. Along these lines, a better understanding the way children view, and attend to, specific media — television, video games, the internet, and personal hand-held devices — might inform what is known about the role the media play in the development of a child's sense of the "real world."

Secondly, the inclusion of biometric measures such as weight and Body Mass Index (BMI) for subjects would be informative in estimating how body shape and size influence estimations of actual exertion versus perceived exertion. In addition, alternative psychological factors, such as body image satisfaction, the feeling of being watched, frustration, and self play vs. competing, may moderate the effects of exergames. More importantly, much of the premise of this study centers around the findings of previous content analyses reporting the lack of physical activity in advertisements and television programming. Thus, gaining better understanding of the specific content viewed is all the more relevant. We would argue that it is only in understanding the correlates of low health literacy that we can find ways to improve children's health literacy through intervention programs like the one tested here. Through the findings of this study it is our hope that exergames can change children's' perceptions of physical activity by providing a fun, enjoyable and engaging alternative to traditional exercise.

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Chapter 13

PARENTING A CHILD WITH A RARE GENETIC DISORDER

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Parenting a child with a rare genetic disorder has special difficulties, because diagnosis may be delayed or undetermined, support groups may be small and geographically scattered, and healthcare skills and resources limited. Ectodermal dysplasia (ED) is a life-limiting condition of the central and peripheral nervous systems. It is associated with significant infant morbidity and mortality, with risks greatest in the first two years of life. For parents caring for a child with ED, this period is often a time of stress and uncertainty. Currently, there is a dearth of literature which reports on the experiences and support needs of parents caring for a child with ED. The aim of this chapter was to provide an in-depth account of the experiences and supportive care needs of parents caring for a child with ED. Methods: A mixed methods design was employed which used focus group data to aid in the development of an internationally distributed internet survey. Results: 126 parents from 14 countries responded to the survey. Five themes were identified; the need for early diagnosis, breastfeeding difficulties in mother carriers with ED, parental decision making, relational impacts and social support issues. Discussion: To our knowledge, this is the first study which identified and examined the experiences and support needs of parents within this rare genetic disorder. Further research into the areas outlined in this study is warranted to expand the knowledge and awareness gaps.

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INTRODUCTION

Ectodermal dysplasia (ED) is a rare genetic disorder with an incidence of 1 per 100,000 live births worldwide (1-3). It is a life-limiting condition of the central and peripheral nervous systems affecting tissues and organs of the ectoderm; skin, hair, nails, teeth and sweat glands (4). ED is associated with early infant morbidity and mortality due to some of the more significant physiological traits (5, 6). The most significant is the risk of overheating, suffering life-threatening seizures, mental retardation and in 30% of cases death (5, 7, 8).

Parents of a child with a genetic disorder describe their experiences as often stressful, exhausting and at times overwhelming (9). They voice feelings of inadequacy and disillusion to provide for their child's individual needs especially in the early years of life. There is widespread recognition that caring for a child with a genetic disorder places significant burdens on family members, their relationships and ability to cope with the daily requirements within the family structure (10, 11). While some families are strengthened and unified by the challenges of caring for a child with a genetic disorder, for others, the constant struggle to cope exhausts their resources (11). It is common for parents, especially mothers, of a child born with a genetic disorder to blame themselves for their child's condition (12).

Instead of receiving support and feeling socially connected, parents of children with special needs often feel isolated from the mainstreams of family and community life (13).

A search for definitive diagnosis is one of the most frustrating experiences for parents of a child with a genetic disorder (14, 15). It is important for them to have a diagnosis or a 'label' to explain their child's condition (16). A delay in diagnosis for parents makes it challenging to depict the future course of their child's illness increasing their levels of stress and uncertainty about their child's future health needs (16).

Parents have declared that for them it is important to have knowledge of the nature and potential outcomes of their child's condition, in order to assist them deal with the present and effectively plan for the future (14). For example, Ritcher (17) stated, that parents caring for a child with ED voice frustration regarding the lack of useful and accessible information available to assist them to care for their child. Often the only accessible literature available to parents is scientific and medically based, and reading the material only serves to heighten parents' levels of fear and anxiety (17).

To date, most published work in the area of parental support needs concerns genetic disorders in general. There is a dearth of published literature on specific rare genetic disorders, where it is likely that parents may have different needs depending on the child's symptoms and health condition. This study aims to address this gap with respect to ectodermal dysplasia by providing information on the support needs of parents with a child with this rare genetic disorder.

OUR STUDY

This was a mixed methods study where a focus group was undertaken as an exploratory investigation into the experiences of parents of children with ED for the purpose of constructing a questionnaire to be used in an international web-based survey. The focus group was held in 2011 with eight parents (six mothers and two fathers) of children diagnosed with

ED. Participants were recruited from a national ED convention held in Sydney Australia. Although with most qualitative research several focus groups would generally be undertaken, the rarity of the disorder and the availability of parents at the national conference provided a unique opportunity to obtain this data. The focus group lasted approximately one hour, and the session was recorded and later transcribed.

The analysis of the focus group data endeavoured to disclose the experiences and supportive care needs of parents caring for a child diagnosed with ED using a straight qualitative descriptive approach, as outlined by Sandelowski (18, 19). Five main themes were identified; the need for early diagnosis, breastfeeding difficulties in mother carriers with ED, parental decision making, relational impacts and social support issues. These themes were then used as major sections in the subsequent internet-based survey.

An initial questionnaire comprising of around 50 items was developed. Apart from the five themes, the opening section of the questionnaire asked general questions about their family, how many children they had and of those, how many had ED. The final section of the questionnaire was for demographic information, including country of residence. As well as closed questions, mainly in the form of multiple response items or 5-point Likert type scales, there were a number of open-ended questions throughout the questionnaire.

This study used the web-based software Survey Monkey (www.20) as the medium for designing and distributing the questionnaire. In order to recruit respondents, a variety of approaches was used including promotion through national and international ED support groups, paediatric hospitals and genetics departments, service clubs and community groups.

The President and Vice President of the Australian National Ectodermal Dysplasia Association were approached and asked to assist in assessing the reliability and validity of the questionnaire. For validity, the above experts were provided with a draft of the questionnaire containing three extra items at the end of the questionnaire asking whether the questions appeared to have face validity, whether there were any questions that they felt should be omitted, and whether there were additional questions that they felt should be added. Suggested changes were carried out and a second questionnaire was forwarded to them a week later. There were almost identical responses between the first and second surveys, demonstrating adequate reliability.

The survey remained open for one month. When the survey was closed, the data were transferred to the SPSS 20 statistical package for analysis. Since there was no sampling frame, it was not possible to provide response rates. Data were first analysed using descriptive statistics. Counts and percentages were obtained for categorical variables, and means and standard deviations for continuous variables, for example, factors associated with breastfeeding issues, were assessed by Chi-squared tests.

With respect to ethics, potential participants in the focus group were provided with an information sheet and consent form which they completed. For the survey, consent was obtained when participants completed the questionnaire online. The study received the appropriate ethical clearance from the University of South Australia Human Research Ethics Committee (Protocol no. 0000024368).

FINDINGS

In all, 126 parents responded to the survey, the majority (92%) being mothers. The age of respondents ranged from 15 to 66 years, with a mean (SD) age of 40.1 (8.8) years. Most respondents (84%) were in a married/de facto relationship. The remaining were widowed (4%), separated or divorced (7%) or single/never married (5%). Details of the country of residence of respondents are provided in Table 1. The majority of parents were from the United Kingdom, Australia and United States. With respect to occupation, 68% of respondents were working as full-time wage earners, 9% as part-time wage earners, and 24%were stay at home parents. When asked whether having a child with ED impacted on their or their partner's employment status, 29% said that it had.

One quarter of parents (25%) stated that they themselves had been diagnosed with ED. Of these parents, 22/32 (69%) said that they had been diagnosed as an adult. In the majority of cases, 18/21 (86%), this was following their child's diagnosis. Notably, only five parents stated that their child was diagnosed with ED before birth. This apparently was as a result of either having ED themselves, already caring for a child with ED or as a result of investigations being undertake during pregnancy because of observed physical abnormalities. Nearly all respondents (92%) recalled having a significant emotional response to receiving a diagnosis of ED in their child.

Parents in the survey were asked to describe a single advantage for receiving an early diagnosis of ED. Comments included: appropriately manage child's temperature (25%); be able to provide appropriate care and minimise risks (21%); access to support, resources and treatments (10%); answer questions, peace of mind and reduce concerns (8%); planning for the future (5%).

When asked whether they had experienced any difficulties breastfeeding, many mothers 51/116 (44%) indicated that they had. When mothers who themselves had ED were compared with mothers who did not have ED, there was a consistent pattern of mothers with ED having a greater risk of breastfeeding difficulties (see Table 2).

Table 1. In which country do you currently live? (N = 113)

Variable	n	%
Australia	25	22.1
Bangladesh	1	0.9
Belgium	2	1.8
Canada	6	5.3
Germany	3	2.7
India	1	0.9
Iran	1	0.9
Ireland	5	4.4
Israel (Palestinian Arab Authority)	1	0.9
Poland	2	1.8
Slovakia	1	0.9
South Africa	2	1.8
United Kingdom	39	34.5
United States of America	24	21.2
Total	113	100.0

Table 2. Difficulties experienced breastfeeding (N = 116)

Problem	Mother does not have ED (N = 86)		Mother has ED (N = 30)		RR	95% CI RR	Sig.
	n	%	n	%			
Lack of milk	12	14.0	6	20.0	1.43	0.59 – 3.48	0.431
Sore nipples	10	11.6	8	26.7	2.29	1.00 – 5.27	0.050
Baby took long time to feed	15	17.4	9	30.0	1.72	0.84 – 3.51	0.144
Baby not happy after feed	11	12.8	8	26.7	2.08	0.93 – 4.69	0.077
Loss of breast tissue	2	2.3	2	6.7	2.87	0.42 – 19.46	0.262

Respondents were asked whether having a child with ED had impacted on their other children. Over half of those who responded 55/93 (59%) said that it had with comments being both positive and negative.

Respondents were asked whether having a child with ED has impacted on their relationship with their partner. Over one third 41/121 (36%) said that it had. Many parents commented on this aspect of their lives, and surprisingly, there appeared to be both positive and negative impacts for the parents. Due to the impact on their lives and daily responsibilities of caring for a child with ED, 53/119 (44%) of respondents said that they chose not to have any more children following the birth and diagnosis of their child.

Primary sources of information about ED were from ED support groups (63%), internet sites (61%), and from the specialist (41%). The majority of respondents (78%) said that they were either satisfied or very satisfied with the information. Not surprisingly, for the majority of parents, primary support came from within the family. Respondents were asked to rate their level of satisfaction with specialist support. More than half 60/113 (53%) were satisfied or very satisfied with the support they received. When asked whether they would have liked more support, 84/112 (75%) said that they would. In the questionnaire, parents were given the following scenario:

> "The Government only has limited money to support services for parents of children with ED. If all of this money is worth 100%, what percentage would you vote for each of the possible support options below?"

Table 3. Preferred support resources (N = 107)

Variable	%
A suitable written/web-based ED support package available for parents	13.4
Regular contact with a Nurse Specialist in ED	16.0
Cooling aids and other resources available (e.g., cooling vests, sprays or other cooling aids)	15.1
Regular contact with an ED peer support person	14.1
Air-conditioning installed in the home	12.9
Additional time to talk to a Dentist/ Dermatologist/Lactation Consultant/Midwife/ Counsellor or other Specialist Clinicians	19.5
Other	9.0
Total	100.0

Of the respondents who completed this question, allocation of resources was quite evenly spread between the various supportive care options (see Table 3).

DISCUSSION

Only five parents in this study reported that their child was diagnosed with ED before birth. Nearly all parents in the survey would have preferred an earlier diagnosis of ED for their child. Unfortunately, with the present state of diagnosis this is unlikely to happen soon. Diagnosis of ED remains a complex and protracted process for parents, relying heavily on key physical features. However, the recent establishment of an international registry of affected individuals by the National Foundation for Ectodermal Dysplasia (NFED) will eventually lead to a better understanding of the genotypes involved and may allow for better screening and earlier diagnosis (4).

An implication is the need for doctors, nurses and other health professionals to have a greater awareness and understanding of ED and the potential impacts that this rare genetic disorder has on affected infants in their first two years of life. Currently, genetics does not feature strongly in curricula across a number of disciplines and there is a need for genetics to be integrated and incorporated into them (21). For now, diagnosis will likely remain the remit of parents and their self-determination to understand what is wrong with their child. The most common response experienced upon receiving a definitive diagnosis of ED for their child was "relief." With diagnosis of ED being difficult to obtain and often delayed, it is not surprising that the parents in this study felt relieved to finally receive a conclusive term which describes their child's unique and complex illness.

It appears that education regarding ED and knowledge about how to care for and meet the individual needs of their child with ED was largely influenced by receiving a definitive diagnosis of ED. Information was primarily obtained from ED support groups and internet sites followed by specialists. Most parents were satisfied with the level of information available and felt that it assisted them in making informed and confident decisions on how to provide care and meet the needs of their child with ED.

This study revealed a phenomenon not previously identified in the literature; mothers who have ED themselves are more likely to experience difficulties breastfeeding than mothers without ED. A number of mothers in this study commented on how traumatic breastfeeding was for them and the struggles that they faced in those first few days of their newborns life, more so, for mothers who were carriers of ED. They also commented on receiving a lack of support from midwives and lactation specialists when they most required it, and stated feeling judged by them because they were unable to successfully breastfeed.

Parents in the survey described the relational impacts between their child with ED and the other siblings to be both positive and negative. Many parents admitted that the other siblings simply did not get enough of their attention. In many situations, parents felt they had to put their ED child first and that the other siblings just had to fit in.

Parenting a child with a genetic disorder has profound physical and psychological health implications to parents and their relationship with each other (11, 22, 23). This was true for parents in the survey, with one third of parents stating that having a child with ED has impacted on their relationship with their partner; either in a positive or a negative way. For more than half of parents surveyed, a decision not to have further children following their child's diagnosis of ED was identified. Parents, stated that they did not want to risk another pregnancy, that they were scared that the next baby would have ED and that the symptoms might be worse. Not surprisingly, these feelings are commonly shared amongst many other parents caring for a child with a genetic disorder.

The majority of parents in the survey said that their primary support came from their partners and other family members, followed by internet sites. According to Gunn et al. (24), family play a central role in providing the emotional, practical and psychological supports to parents who are caring for a child with a genetic disorder. With regards to specialist support, parents' experiences were very different from those of family support. Scarcely half of the parents surveyed said that they were satisfied with the level of specialist support that they had received for them and their child with ED, especially during the diagnosis period. In fact, two thirds of parents in the survey would have liked more support from specialists. The issue is not that parents in the survey had unreasonable expectations of specialists; rather, they assumed that specialists would be better aware and informed about ED in order to provide them with the necessary level of information and support. These unmet expectations of parents resulted in dissatisfaction and disappointment.

The main limitation to this study was the availability of parents of a child with ED. With such a rare genetic disorder, parents of a child with ED are few, difficult to contact and geographically scattered making it problematic to obtain the required information.

CONCLUSION

In conclusion, this study is the first to report on the support needs of parents caring for a child with ED. It has uncovered previously unknown issues related to breastfeeding for mother carriers of ED, and points to the need for further research into the support needs of parents with ED and other rare genetic disorders.

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Chapter 14

MOTHERS RECOVERING FROM SUBSTANCE ABUSE AND CHILD MALTREATMENT

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Parents with a history of substance abuse are at high-risk for child maltreatment, including the neglect of their child's health (medical neglect). Additionally, these parents are likely to have low health literacy levels, possibly further jeopardizing risk to their child's health. This research examined the effectiveness of the SafeCare® Health Module for mothers in a residential recovery facility. Two mothers with children under age five were trained to 1) identify child health symptoms and illnesses and 2) to determine the most appropriate course of care. Using a multiple-baseline, single-case research design, mothers were evaluated in their ability to select the most appropriate care setting using decision-making behaviors in response to a prompted child health scenario. The mothers showed steady improvement in skill acquisition. Future research directions and intervention implementation implications are discussed.

INTRODUCTION

Child maltreatment includes harmful acts committed against children (acts of commission), as well as negligent behaviors (acts of omission) that affect a child's well-being. These might include physical abuse, failure to provide for a child's emotional and physical needs (neglect), psychological abuse, and sexual mistreatment (1). In 2011, an estimated 3.7 million children had at least one report to Child Protective Services, of which, 18.5% were substantiated. Over 78.5% of these substantiated cases were attributed to neglect (2). Medical neglect accounts

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for a relatively small percentage of general child maltreatment, however, this type of neglect was associated with 96 of the 151 (or 7.6%) child fatalities in 2011 (2). Medical neglect is defined as the existence of unmet basic health needs and is typically the result of the failure to heed signs of illness or the failure to follow medical advice once sought (3, 4).

The association of child maltreatment and, in adolescent and adult years, high-risk behaviors, including early initiation of substance use, substance abuse, depression, cardiovascular disease, and early mortality is well documented (5-7). Although all forms of maltreatment may produce negative physical and mental health outcomes, neglect is of particular concern because of its high prevalence.

Parental substance abuse increases the likelihood of child medical neglect and places the health of a child in jeopardy (7, 8). According to the National Survey on Drug Use and Health, in 2009 approximately 22.6 million Americans over the age of 12 years were classified as substance abusers or substance dependent (9). The 2002-2007 data from the same survey indicated that over 8.3 million children under 18 years of age (11.9%) lived with at least one parent who was substance dependent on or abused alcohol or an illicit drug during the past year (10).

The relationship between parental substance abuse and the perpetration of child neglect is well-documented. Ondersma (8) investigated factors common in families with low socioeconomic status (substance abuse, negative life events, depression, and social isolation), and explored the factors' ability to predict the occurrence of neglect. Substance abuse was found to be the strongest predictor of neglect. Specifically, a child in a family with a history of substance abuse was 18.35 times more likely to experience neglect. Brown and colleagues (11) examined demographic, familial, parenting, and child factors association with neglectand found that maternal sociopathy (i.e., alcohol, substance abuse, or problems with the police) produced the highest odds ratio for neglect. Paternal sociopathy also produced significantly predicted neglect. Among substance abusing mothers, parenting skills such as feeding, knowledge of child development, and care for newborns were low, but showed a significant increase after receiving a parenting intervention tailored to substance abusing mothers in treatment (12). Thus, mothers struggling with substance abuse issues fared well in parenting interventions and show an increase in skill demonstration.

SafeCare®, an evidence-based parent-training intervention, is delivered in the home to mothers at-risk for abuse and neglect and has proven effective in increasing health knowledge and skills (13-15). SafeCare focuses on improving parental skills in three core areas: parent-child/parent-infant interactions, home safety and child health. The Health Module teaches parents to use professionally validated health reference materials, preventative techniques, how to identify symptoms of childhood illnesses or injuries, and when to seek professional treatment by following the steps of a task analysis. Further, interventions targeting parents' health literacy may improve parents' understanding of their child's health needs, thus reducing the occurrence of medical neglect.

In the prevention of medical neglect, health literacy becomes relevant. Health literacy is defined as an individual's capacity to obtain, process and understand basic health information and services leading to the appropriate health-seeking behavior (16). Low health literacy has been associated with higher rates of hospitalization and is often not detected by physicians in typical office visits (4, 17). Interventions tailored to improve parents' health literacy using written materials have shown the potential for societal and financial benefit (18). In the SafeCare Health Module, parents are trained to utilize health reference materials, maintain health records, and to make informed decisions about care settings, improving parental health literacy.

Due to the strong evidence of an increased risk child maltreatment among substance-abusing parents, it is expected that mothers in recovery could benefit from the SafeCare Health Module. SafeCare had not previously been implemented specifically with mothers being treated for substance abuse; nor had it been implemented in a residential recovery setting. Thus, potential social and environmental factors associated with this setting, as well as population characteristics could influence an evidence-based program in some nature. The purpose of the present research was to explore if mothers in a substance abuse residential recovery setting could acquire and master skills related to the identification of and care for children's illnesses and injuries.

OUR STUDY

Two mothers were selected from a comprehensive residential recovery program for women with and without children. Demographic data are presented in Table 1. Both mothers were single, African-American and under 30-years old. Each was unemployed initially, but one mother began a job during intervention. The highest level of education completed was high school; one of the mothers had completed at least some high school and one had obtained her GED. Mother 1 had two children under age 5, both living with her in the residential facility. Mother 2 had four children, two of whom were under age five, one of whom was living with her at the facility.

The program admission coordinator and residential counselors assisted with recruitment by generating a list of eight women who met the study inclusion criteria: 1) had at least one child under age five; 2) had a treatment plan that suggested the mother would be a resident of the program's community housing for the duration of the data collection process; 3) possessed characteristics of a successful participant in the recovery program based on the opinion of the experienced admission coordinator and residential counselors, such as adherence to program rules and regulations and participation in program activities, group, and individual counseling sessions and 4) expressed an interest in participating. Three mothers initially met the criteria and were available. One mother demonstrated such a high level of skills across all decision-making behaviors in the baseline condition, the data could not show any relationship between the Health module and her performance.

Table 1. Participant information

Mother	Age	Marital Status	Race	Education Level	Employment Status	Total Number of Children	Number of Children (0-5)
1	22	Single	African-American	Some High School	Looking for employment	2	2
2	29	Single	African-American	Some High School	Unemployed	4	2

Table 2. Parent satisfaction survey results

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	Caring for my child's health when he/she is sick or injured has become easier	1/2	1/2			
2.	Deciding when to take my child to the doctor has become easier	1/2	1/2			
3.	Deciding when my child needs emergency treatment has become easier	1/2	1/2			
4.	I believe that this health training would be useful to other parents	2/2				
5.	I do not feel the health training gave me new or useful information or skills				1/2	1/2
6.	Practicing during the sessions was useful	2/2				
7.	The written materials were useful	2/2				
8.	The Home Visitor was on time to appointments	1/2	1/2			
9.	The Home Visitor was warm and friendly	2/2				
10.	The Home Visitor was negative and critical					2/2
11.	The Home Visitor was good at explaining the material	2/2				

Setting

The SafeCare Health module training was conducted in the living rooms of the mothers' respective apartments. The residences, provided through the recovery program, were fully furnished and included a living room, kitchen, bathroom, and at least two bedrooms. One of the mothers shared the apartment with another participant in the recovery program. The other mother lived with two roommates participating in the recovery room.

Observation system

The data collection tool used for the Health module was the SafeCafe Sick or Injured Child Checklist Home Visitor Version©(SICC-HV). The SICC-HV provides ordered steps that a mother should take when her child presents the symptoms or problems listed on a specific scenario card. Mothers are provided various health scenarios that require one of the following courses of action, or decision-making behaviors: Call the Doctor (CD); Treat at Home (TH); or, Go to the Emergency Room or Call 911 (ER).

There are varying numbers of ordered steps in a decision-making behavior based on the type of scenario. There were a total of 14-steps to be completed for the TH scenarios, 6-steps for the CD scenarios, and 3-steps for the ER scenarios. Regardless of scenario type, the first two steps were to identify and state symptoms and assess additional symptoms as needed. The subsequent steps varied based on the appropriate treatment. For the ER scenarios, one additional step was required: Go to the ER or call 911. For the CD scenarios, the additional steps included: completing the relevant portions of the Health Recording Chart, calling the doctor's office, describing the symptoms correctly to the doctor, and asking for or accepting an appointment. For the TH scenarios, the steps were divided into three different stages: First Check, Follow-up 1, and Follow-up 2. For the First Check the steps included: looking up symptoms/illness in the reference guide or consulting a health professional, completing the Health Recording Chart, stating and administering appropriate treatments correctly, reading instructions on medicines or getting specific instructions about medicines from the doctor, and recording the treatment and dose correctly. The steps for Follow-up 1 and 2 were to check the symptoms again after the recommended time, continue the treatment if the symptoms are still present, and record the time, symptoms, treatment, and dose correctly on the Health Recording Chart.

The Home Visitor (HV; lead author) scored each ordered step on the SICC-HV with a plus (+), a minus (-), or an N/A based on the acceptable responses listed on the Scenario Answer Sheet. At the end of the scenario, the HV added up the total number of steps completed correctly and the total applicable steps. The total number of correct steps was divided by the applicable steps to calculate the percent correct for the scenario.

Home visitor training

The Home Visitor (HV) and Reliability Observer (RO) were trained to deliver the SafeCare Health module in a face-to-face six-hour training session conducted by a SafeCare Training Specialist from the National SafeCare Training and Research Center (NSTRC). The training consisted of a didactic presentation of the material and practice role-playing the scenarios with the trainer. After meeting role-play mastery criteria, the HV and RO completed a 26-item fill-in-the-blank and true/false assessment. The HV and RO met the criterion of a score of 85% or better and were, thus, certified to deliver the Health module.

Reliability

The HV and the RO, a graduate research assistant, established reliability criterion of 85% or better prior to the initiation of the study by viewing video recordings of prior health module sessions conducted by other home visitors. Interobserver reliability was measured in all baseline sessions and one intervention session for both mothers. Interobserver agreement was established for baseline and subsequent intervention conditions by comparing the individual scores (plus or minus) of the HV and the RO for each applicable ordered step on the SICC-HV. If the HV and the RO scored an ordered step identically, this was considered an agreement. If the HV and the RO had different scores for the ordered step, this was considered a disagreement. All interrater sessions were above the 85% cut-off. Interobserver agreement was calculated by using the formula: number of agreements divided by the sum of all agreements and disagreements multiplied by 100.

Materials

Mothers received a health manual, a professionally validated resource guide. The health manual includes forms for the mother to write down basic health information for each child, a copy of the health recording chart (a tool to document health events), prevention techniques (guides regarding basic topics such as hygiene or hand washing), and the symptom and illness guide (an indexed resource of common health events, such as pink eye or a cold, and steps to determine how to best care for the symptom or illness). The mothers also received the Sick and Injured Child Checklist – Parent Version, a parent version of the steps taught to evaluate health events. This document provides a prompted step-by-step checklist allowing the mothers to determine the most appropriate course of action (TH, CD, ER). In addition, the mothers were provided with a health kit. This supply kit included basic home medical supplies, including, but not limited to: a digital thermometer, antibiotic ointment, and diaper cream. Additionally, to each session the HV brought copies of the observational tool (SICC-HV) and a book of health scenarios, from which the assessment and training of the mothers skills was based.

Consumer evaluation

Upon training completion of the Health Module, mothers filled out the Parent Satisfaction Survey, a one-page document which aims to assess the mothers’ perceptions of the program’s utility and the training skills of the HV. The survey consisted of 11-items rated using a Likert-scale ranging from 1 (Strongly Agree) to 5 (Strongly Disagree). Additional space was provided for comments.

Experimental design

A multiple-baseline design across behaviors replicated across mothers was used to evaluate the effects of the intervention. The order of training for the three decision-making behaviors (TH, CD, and ER) was based on baseline data. Behaviors with the most stable scores were trained first. Stability (no change) or a downward trend in baseline determined when intervention could begin. Behaviors that showed upward trends were not trained until stability was established. Data were collected face-to-face via the SICC-HV during each session with each mother. A multiple baseline design across behaviors demonstrates internal validity; by staggering intervention in one skill set until skill acquisition occurs and then introducing intervention in subsequent skill sets in the same manner. If skill acquisition only occurs after intervention is initiated, other explanations for the change in skill acquisition can be ruled-out.

Experimental procedure

The SafeCare Health module is designed to teach mothers how to identify and respond to their children's health-related symptoms. The intervention is typically delivered in six sessions. In single-case research designs, the number of sessions varies dependent upon trends in data and skill acquisition (19).

Orientation and Baseline. During the first visit, following consent, the HV provided an overview of the Health module, including the goals and expected outcomes of training. The mothers then completed a demographic survey, a one-page form asking basic questions such as race, marital status, and household income.

The HV collected baseline data using the SICC-HVfor each of the three decision-making behaviors (TH, CD, ER). The HV handed the mother a scenario card with a health symptom or problem that her child could experience, but may not have actually experienced. The mother was instructed to read the scenario aloud. After the mother had finished reading it, the HV followed the steps on the Scenario Answer Sheet, which provided scripted dialogue and sequenced actions for the HV in response to the mothers' answers. The HV did not provide any feedback or training to the mother during baseline.

Next, the contents and structure of the Health Manual were presented and discussed. The session was summarized and the mother's assignment, readings to complete in the health manual before the next session. Visits continued until baseline data were stable or declining, indicating it appropriate to intervene.

Intervention/Training. Training on each of the three scenario types (ER, CD, TH) occurred through didactic presentation, modeling of decision-making behaviors by the HV, and the mothers' practice of using a step-by-step procedure related to the health skills and the health reference manual. The order in which the scenario types were taught varied by mother and was determined by baseline data, which were collected for each of the decision-making behaviors on which the mother had not yet received training.

During the first training session, the HV explained how to use the health manual as a resource for looking up information on children's symptoms and illnesses. The HV explained the purpose of the SICC-P and subsequently modeled the ordered steps of the SICC-P using a scenario of the relevant decision-making behavior. The mother was then prompted to practice the steps of the SICC-P using the same scenario that the HV modeled. The HV gave praise and corrective feedback. In the following sessions, several decision-making behaviors were practiced at a time and the mother used the SICC-P and the Health Manual to decide the appropriate course of action to take for the presented scenario. The HV continued to provide feedback and encouragement to the mother. Portions of the health reference manual were also assigned by the HV for the mother to read between sessions.

The mother was required to demonstrate mastery of the skills in each scenario type before moving on to next scenario type. Mastery for the CD and TH scenarios was established as a score of 80% steps correct and mastery for the ER scenario was established as 100% steps correct. Mastery criteria were determined in concert with the SafeCare developer based on the criteria used in previous SafeCare Health Module studies and a judgment of a reasonable number of steps that the participant could complete correctly. Data to determine each mother's mastery of scenarios that were recently taught were collected at the beginning of each training session prior to any new training.

The mother used the Health Manual as a reference during data collection. After the data collection, the HV continued to train the scenario type if mastery was not achieved, providing the mother with feedback to reinforce positive behaviors and correct missed steps.

Follow-up. The HV observed the mother's performance as she demonstrated one role-play for each scenario type (TH, CD, and ER) at one-month postintervention. Mothers received a $25 gift card to a local discount store after the completion of her follow-up visit.

FINDINGS

For both mothers, reliability observations occurred during baseline sessions and one training session. Interobserver reliability was maintained at 93% and above over the duration of the study. The mean reliability score for all observed sessions was 100% for Mother 1 and 93.8% for Mother 2.

Baseline

Figures 1 and 2 show the effects of the Health Module intervention for Mother 1 and 2, respectively. During baseline, both mother's scores were below the mastery criterion for CD and TH decision-making behaviors. Both mothers achieved scores of 100% correct after three baseline sessions for the ER decision-making behavior. Thus, no training was necessary for the ER scenarios. Mother 1 displayed a decreasing trend for CD skills and an increasing trend for TH skills, achieving a score of 58% correct during the second baseline session. This skill set became stable after four baseline sessions. Mother 2 also showed a decreasing trend in scores for CD skills and instability for TH skills.

For Mother 1, training began with CD because of a descending trend from the second baseline session and an increased score for TH. After receiving training for CD, her score increased from 16% correct to 66% correct in session 3. The data dropped slightly in session 4, but remained stable at 100% in subsequent sessions. Baseline data collection continued for the TH until the data became stable. Training began during Session 4 with a score of 53% correct. Although in session 5 her score dropped to 33% correct, in the subsequent sessions her scores increased steadily.

For Mother 2, training also began with CD after data showed a decreasing trend. After intervening in session 2, data dropped from 66% correct to 33% correct in session 3, however, the data increased in the next session. Data generally increased with the exception of session 7, the mother consistently achieved 100% mastery. For TH, stability was attained after seven baseline sessions. After training, data increased significantly, from 15% correct to 83% correct, and mastery was maintained during the remaining sessions.

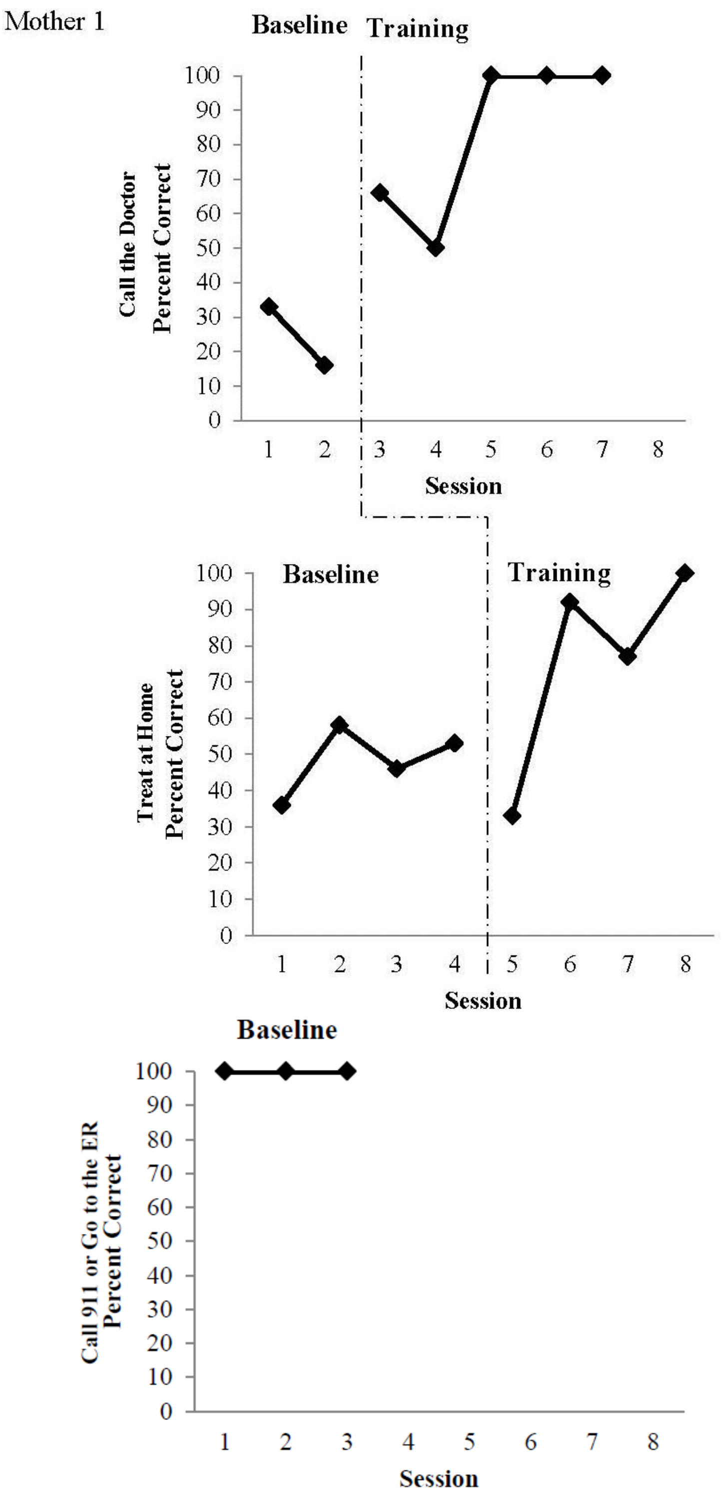

Figure 1. Percent correct for each skill set.

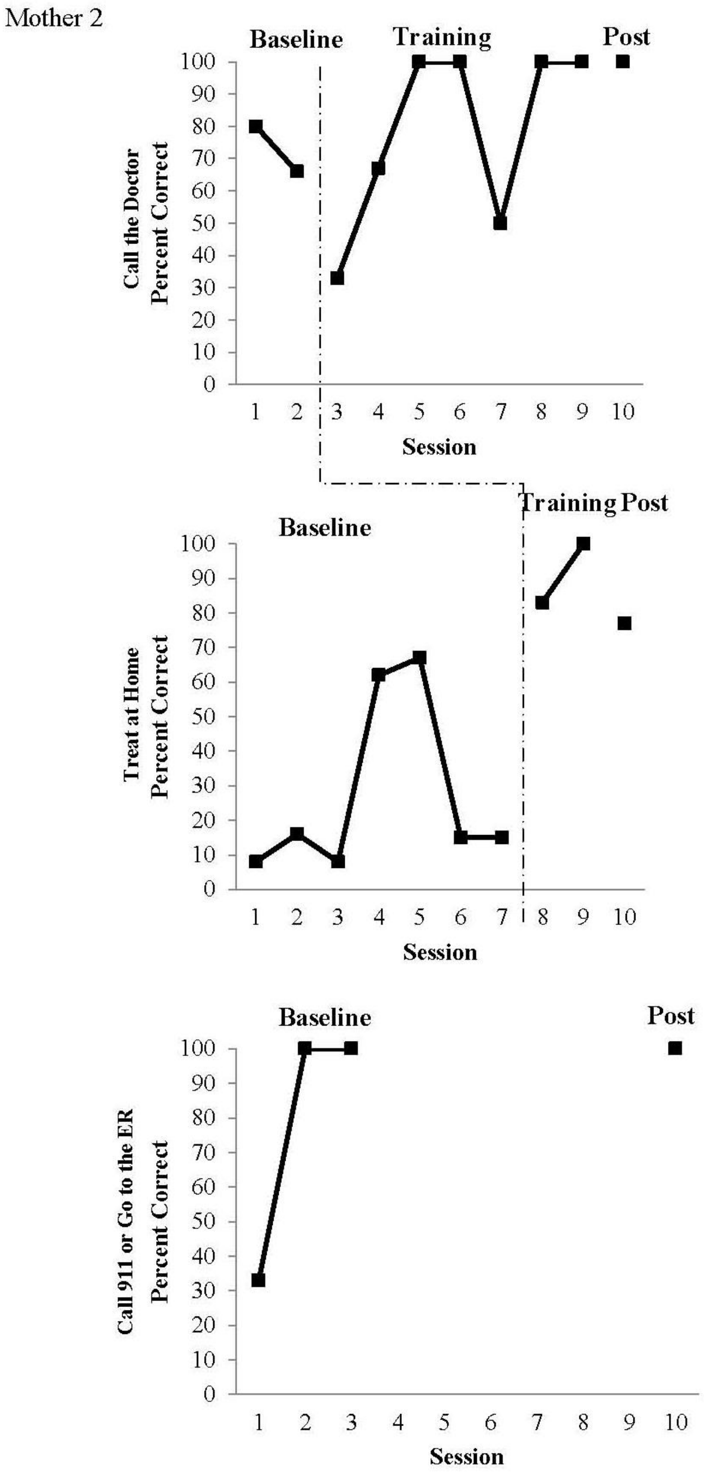

Figure 2. Percent correct for each skill set.

Follow-up

Mother 1 was not available for follow-up. Mother 2 showed mastery of CD and ER with 100% correct for each behavior. Data were 77% correct, slightly below the mastery criterion of 80%, for TH; thus, additional training was delivered during the follow-up session.

Consumer evaluation

Both mothers indicated on their Parent Satisfaction Surveys that the training and written materials were useful, and that they believed the training would be helpful to other parents. When asked if the training had made it easier to decide when to go the emergency room and when to call the doctor, both mothers responded favorably. The mothers also responded positively when asked if caring for their sick or injured child had become easier. Both mothers also responded favorably when asked if deciding when to take their child to the doctor has become easier and strongly agreed that the training would be useful to other parents. Their survey responses and written comments also indicated that they found the HV to be knowledgeable and friendly.

CONCLUSION

Mothers who abuse substances are at an increased risk for medical neglect (7, 8) and have been associated with low health literacy levels, or aa lack of comprehension concerning the child’s health care (4). This study sought to examine the efficacy of the SafeCare Health Module when delivered to mothers enrolled in a residential recovery program who have a documented history of substance abuse. We were further able to observe if the setting, a roommate-style apartment home, had any adverse impact on the success of the Health Module intervention.

The intervention was effective in teaching mothers to identify and assess their children’s symptoms and select the appropriate course of action for the symptoms described. Skill acquisition occurred gradually and at the conclusion of training; both mothers achieved 100% mastery of the three decision-making behaviors: CD, TH, ER.

The mothers did not receive any training for the ER decision-making behavior, because the mothers both demonstrated mastery after three baseline sessions. These results are consistent with the results of Bigelow and Lutzker (14) in which five of the seven participants achieved 100% mastery of the ER behavior after one baseline session and all participants maintained 100% mastery after training. The mothers’ quick recognition of the ER decision-making behavior does not necessarily indicate mastery of the decision-making behavior. Our findings echo current data trends indicating an increased use of emergency rooms rather than preventative care visits (20). It is possible that selecting a visit to the emergency room was the mothers default response to a given scenario. Future research should control for this possibility in the research design. The increased scores for CD and TH decision-making behaviors in fact indicates an increase in knowledge for the ER decision-making behavior.

The other two decision-making behaviors, CD and TH, required further training and the mothers showed gradual progress in mastering the required skills. Assessment of skills occurred at the beginning of each session. While the multiple-baseline design ensured internal validity, it cannot control for the influence of external, social-ecological factors. The variability in the data for Mother 2 indicates that she appeared to adequately understand the skills on some days better than others; however upon completion of training, she met all mastery criteria.

Mother 1 was lost to follow-up; thus, only follow-up data are available for Mother 2. Postintervention scores decreased for Mother 2 in the TH decision-making behavior, which may be explained by social-ecological factors. The follow-up session was conducted after the mother was removed from the program for a rules violation and occurred in the program's administrative offices instead of her apartment home. Mother 1 was more advanced in her recovery than the other participants when training began which may have positively affected her ability to master the Health Module skills.

This setting provided unique challenges, but provided advantages to implementation as well. The sessions were conducted in the mothers' roommate-style apartments where distractions from their children and roommates occurred frequently. The mothers individually disclosed to the HV that they had shared the knowledge and skills acquired through training with other women at the recovery center through informal discussions. Mother 2 stated that she consulted the health manual for a peer whose child had complained of an earache for several weeks. Also, roommates and friends of the participants who had witnessed training being delivered or heard about the details of the training asked to be included in future implementation efforts.

Although the data indicated the health module intervention sufficiently improved the mothers' identification of symptoms and illnesses and use of decision-making behaviors, there are limitations worthy of discussion. First, follow-up data from only one participant are available which limits the generalizability of the data. Second, the impact of social-ecological factors, uncontrolled in this design, potentially explains the variability in data in Mother 2 in the CD skills. More structured, intensive problem-solving may have been useful to address the environmental factors. Early application of this approach could result in fewer distractions, more rapid skill acquisition and also shorter training time. Finally, perhaps most importantly, the mothers were provided the health manual during baseline and thus were able to review the contents on their own and on their own accord. While the HV did not discuss contents or train on the manual during baseline, it cannot be assumed that the mothers did not review pages in between sessions, thus potentially enhancing the outcomes at the beginning of each session.

This research builds upon previous research (13, 14) by examining the effectiveness of the Health Module in a small sample of mothers recovering from substance abuse residing in communal housing. The mothers demonstrated mastery of the skills presented, confirming that mothers with a history of substance abuse can fare well in parenting interventions, even those not structured specifically for the population (12). SafeCare materials provided to the mothers (e.g., the validated health reference manual) and training on how to use the resource and structured steps to determine appropriate treatment (decision-making behaviors) shows promise for improving low levels of health literacy (16).

Future research should explore the potential of a group-based delivery of the health module in a communal setting and should examine the potential of this module with other vulnerable populations such as homeless parents or parents with intellectual disabilities.

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Chapter 15

CHILDREN'S HEALTH AND WELLBEING

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Despite the long tradition in the social welfare field the number of children in Sweden who do not feel well has increased. This statement is based on reports from preschool teachers and includes young children (1-5 years old). The purpose of this chapter is to stress the present situation and what can be done to better work to raise healthy and secure children who also feel well. The aim is to discuss how the quality in preschool affects children's wellbeing? Quality does not only mean happy children and satisfied parents but also competent staff with positive attitudes and systematic quality work. It appears from research that enough time for pedagogical planning and follow-up, small child groups, high teacher density and low staff turnover are also essential. The results also show that the most critical aspects for supporting children's health and development are quality improvements based on equality, an efficient value system, a useful curriculum, scientifically based teacher training and a school/preschool for all.

INTRODUCTION

A majority of all Swedish children attend preschool during the first five years of life, and this period is regarded as one of the most essential periods in child development (1). Wilson (2) argued that influences of preschool 'shape children's social, physical and emotional development long after they start school' (ibid, p.1). The establishment of future abilities with regard to socialisation, security and communication are founded during these years and the most important issue in today's society is to invest in giving all children a good start in life (3).

The population in Sweden was many years ago very homogenous, but this situation has changed during the last decades as a result of the fact that many families with children have left their homes and immigrated to Sweden from other countries. These families have

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different cultures and value systems, but they are also carriers of different experiences, e.g., from war, poverty, unemployment, difficult living situations, and a number of these children have traumatic experiences. This means that Sweden today is a multicultural country, which is also visible in preschool. Although Sweden has a long tradition in the social welfare field, the demands for qualified support for children who do not feel well have increased. Among other researchers Almqvist (4) reported that approximately one fourth of all children in Sweden today have psychosomatic problems and this development must be regarded as serious. This also includes very young children.

The World Health Organization's (WHO's) definition of health is: 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (5. For children this means that wellbeing is based on a functional perspective that is at which degree their health conditions allows them to participate in daily activities e.g., in preschool, how their needs are met and how they can develop their abilities to interact with peers and adults in the environment. Most important are thus children's participation and communication, although WHO thus has a holistic view.

Competent staff in preschool is needed and many pedagogues in Swedish preschools report that the number of children who do not feel physical well have increased and the preschool teachers have noticed that many children grow up in unhealthy environments (6-8). For this reason early intervention is of utmost importance in order to decrease aggressive behaviour, violence, communication disorders and difficulties in establishing social relations (2).

This concerns both immigrant children and Swedish native children. Another observation among the staff is that children with neuropsychiatric disorders e.g., Attention Deficit Hyperactivity Disorder (ADHD) that affect the social interaction as well as children with communication disorders have increased. Children with these difficulties are often involved in conflicts with peers and have difficulties to establish peer relationships (9). In order to promote child development it is essential that the staff in preschool can assess the needs and prerequisites of each child (10, 11). The assessment of the child's abilities is decisive in order to enhance their development, health and wellbeing and early intervention is thus necessary. An area where early intervention is more powerful than late intervention is speech and language delay.

OUR STUDY

This chapter is aimed at discussing how the quality in preschool affects children's health and wellbeing in the Swedish society. The directors of the preschools in a municipality have observed that many preschool teachers experience an increase of children who do not feel well (9, 10). The main issue is to highlight how preschool as an institution can compensate for shortcomings in the child's home as this will result in a preschool that give all children equal opportunities. The article is based on focus group interviews with all municipal preschool directors (N = 4) in a municipality in the south of Sweden. The four directors are responsible for eleven municipal preschools in a municipality concerning their view on the curriculum and on the quality work in preschool as a tool to promote children's health and wellbeing.

The Swedish preschool

The Swedish preschool is based on different social reforms and the Convention of the Rights of the Child (CRC) (12) and it is regarded to be of high quality according to international standards (13). Preschool embraces children between one and five years of age and 94.5 percent of all five-year-olds attend preschool daily. The purpose of the preschool is to meet the parental needs for child care, to support gender equality and to give all children equal opportunities to development, in spite of the fact that school all over the world has main focus on learning and preschool on play and care (14). These researchers stated that the Swedish preschool has not been used to support children's learning, but to strengthen the political agenda. Preschool has a pedagogical and social mission, but is at the same time regarded as a complement to the child's home. Play and learning are corner stones in preschool and most researchers and practicians highlight the importance of play as the dominating activity for learning in childhood (15) and regard play, care and learning as closely related (16-19). Due to this it is necessary that play and learning are integrated as part of children's daily lives. The work in preschool is based on scientific basis and proven experience and the staff are working in teams.

The Swedish preschool also allows parents who are unemployed or on parental leave for a new child in the family have the right to a preschool placement for their other children. Consequently, the majority of the young Swedish children spend the majority of their waken time at preschool who is responsible for raising the children according to the existing culture and value system in society, e.g., Alvestad and Berge (20). The same situation is reported by researchers from other parts of the world (21-23).

The time in preschool is the starting point for life long learning and is expected to be a joyful, secure and stimulating learning environment for children, and the most important persons in a child's life, with exception of the family, are those who they spend their daily activities with, i.e., the staff at preschool. For this reason it is necessary that preschool supports child development and compensate for eventual shortages in the home environment (24, 25). Society is changing continuously, and consequently preschool must change and develop in the same pace.

Previously a child group approximately consisted of 15 children and three teachers, but in 2002 the number of children had increased to approximately 17.5 children and 2.75 staff members (26). This topic is still on the agenda in Sweden and research on the size of the child groups in preschool has recently started in Göteborg (27). However, it appears from research that the number of children in the group is more important than the child-adult ratio (28), but when it comes to the best opportunities for learning Sheridan (29) argues that competent staff is one of the key factors for quality. Small sizes of the child groups are especially vital for children with disabilities. In accordance with the inclusive education policy in Sweden, a majority of all children in need of special support are included in the preschool and for these children small child groups are decisive for their learning. Their difficulties mostly comprise speech and language disorders, concentration difficulties and lack of social competence and this group of children is ever growing in the Swedish preschool (9, 11). The child groups often have children of mixed ages and the children have different backgrounds and experiences. However, preschool is of importance in a lifelong perspective and the Swedish curriculum states that preschool should unit care, education and learning, and the pedagogical mission has been strengthened (30).

A national curriculum for preschool – a way to enhance equity

In 1998 preschool was transferred from the Ministry of Social Affairs to the Ministry of Education and Science. This way the Swedish preschool became part of the common school system (30) with the first national curriculum for preschool (Lpfö 98). The curriculum was revised in 2010 (31) and implemented on July 1st 2011. The reason for implementing a national curriculum was to give all children the same rights to education, learning and development based on the pillars in the Swedish value system: solidarity, democracy, equality between sexes, and equal opportunities for all.

The goals for children's literal and communicative development, mathematical development, nature science and technology were stressed. The special responsibility of the preschool teachers and directors with regard to systematic quality work were emphasized. The corner stones in preschool are learning, play, education and care and in the goals and guidelines of the curriculum the following areas are pointed out as essential for obtaining a good quality:

- norms and values
- development and learning
- opportunities for the child to influence everyday life
- cooperation between preschool and home, cooperation between transition from preschool to preschool class, and between school and leisure time centre
- follow-up, evaluation and development of the preschool.

Many countries have as Sweden today separate curricula for preschool, stating what parents and children can expect of the preschool.

Teacher training

The staff working in preschool includes both preschool teachers and child care workers, i.e., two categories of professionals who work in team. Most pedagogues are aware of their mission to support each child's development, but they are sometimes worried that they are not good enough to assist children who do not feel mentally well. The three and a half year long preschool teacher training in Sweden is based on an academic level, and it is stressed in the Swedish Education Act (30) that preschool should be based on a scientific basis and proven experiences. The importance of competent preschool teachers for children's wellbeing and development is thus decisive for the children's future opportunities.

One of the directors of a municipal preschool said that her job was privileged (11) and she expressed that no other pedagogues than those working in preschool may ever experience such an extensive human development.

> To follow an infant who cannot walk without support and without having acquired a functional language until the child can make things on his/her own and who has developed a rich language – that is a development! (director of a preschool) (authors' translation)

This director highlighted that qualified preschool teachers are necessary for child development and for obtaining high quality in preschool. The director pointed at a substantial topic – the preschool teachers as professionals and their knowledge and competence to see and take care of the abilities and prerequisites in each child. It appears from research (11) that the work of the preschool teachers used to be undervalued as they "only work with small children" and not to teach children to read and write, which has been regarded as much more important.

Research has stressed the importance of a functioning preschool in order to support child development, and the interest in developing preschool as an institution has increased globally. Many studies have shown the importance of preschool for children's health and wellbeing (10, 22, 32). A preschool with a stimulating environment and of high quality will increase children's possibilities to feel good and also compensate for eventual shortages in the child's home environment. That so many of today's children do not feel well is strange despite the fact that we live in a welfare society and despite that Sweden has ratified the CRC. It appears from research that children who get good study results in school also has a higher degree of wellbeing both when growing up and later in life (32). This is obvious also with children at early ages (2).

At the end of the 1990s most of the staff was child care workers but the number of preschool teachers have increased by new recruitments and in-service training of the already employed staff and this has led to the main part of the staff is in many municipalities' preschool teachers. An explanation is that when the curriculum for preschool was implemented in 2011 many municipalities conducted relatively comprehensive education activities for preschool staff. A majority of the preschool teachers felt proud of the revised curriculum and their interpretation was that their profession and activities was up valued. The number of small children increased and this influenced the activities in preschool. At the same time the state regulation about staff density, and how many children that could take part on a certain area was excluded. The dominating goals in the first curriculum were norms and values, development and learning. The revised curriculum has an increased focus on learning and stress speech and language development, mathematics, nature science and technology and children's influence are central. Today learning has a more evident focus, preschool approaches school. Play, learning and development as well as planning, documentation and assessment/evaluating of the activities are central concepts in the revised curriculum for preschool (32). The goals are many and the level of ambition has been increased but the majority working with small children regards many of the goals as self evident while other need more work. The goals are to strive for but nothing guide the preschools how to reach the goals.

FINDINGS

The results show that the directors of the preschools conceive that preschool has developed after implementation of the revised curriculum. "The status of preschool has improved after the implementation. From baby-sitting to a pedagogical activity" (11) commented one of the directors. The director added that the routines for parental meetings, communication, collecting and leaving the child and developmental dialogues have been created. The directors state that the revised curriculum has focus on the goal directed learning processes but in school children's abilities are in focus and what children should learn and develop. A change pointed out by the directors is the stress on competence of the preschool teachers and that this aspect is stressed in the revised curriculum. They mean that this was not that obvious earlier. Their interpretation of the curriculum is that the preschool teachers are responsible for the intentions in the curriculum to be followed and for this reason a greater responsibility to support the teachers in order to live up to the intentions. Their job is to give support for implementation. The child care workers are not mentioned in the curriculum and those who have been working with small children in many years argue that they have the same tasks as the preschool teachers and feel completely disregarded. The directors state that they must lift the discussions to a pedagogical level and get the different professional groups to see the strength of each group. This is important when it comes to the six-year-olds who today attend the preschool class and the children in the preschool group are younger.

The directors point on the necessity to created security and routines in preschool in order for the children to feel safe, respected and confirmed. There is also a need to listen to the children's voices (CRC) in order to make each child participatory in the activities. Consequently communication and socialisation have an essential role in preschool, although the teachers point out that they learn together and that learning is to share.

If the stand point is that the quality in preschool influence children's wellbeing several aspects must be highlighted. One is about the staff and that there is a stability and continuity in the staff group, another that the immediate physical and psychical environments are challenging and developing. The directors of the preschools think that it is difficult to separate care from learning and that the combination is a great pedagogical challenge. They require a greater cooperation with the preschool class and what has started in preschool should continue and be further developed in the preschool class. One example is the subject nature science and another speech and language development. "Language development is an important area as children with speech and language disorders have increased" (comment by one of the directors).

Evaluation and visualisation of children's learning

It appears from the curriculum that the preschool directors are responsible for documentation, follow-up and analysing and embrace how children's skills and knowledge is continuously changing in relation to the prerequisites in preschool. They experience that it is difficult to assess children's individual learning in preschool – they shall work in group but at he same time see "where each child is" and how to develop the child's abilities. Our interpretation is that the preschool staff must assess the development of the individual child in order to support further development.

Most parents do not ask what the child has learnt in preschool, they wonder if their child has a good development, talk as expected in that age… can listen and participate in the group.

Other areas of interest for the parents are peer relations, if the child takes contact with other children and how the basic needs functions, e.g., how the child is eating. The preschool directors are concerned about this and if this is kind of assessment. All preschool teachers have in their education learnt about child development and react if a child does not develop in the right direction and they argue that this is a way to assess the child. What the preschool teachers tell the parents is also an evaluation of the child's skills and abilities. Sometimes the parents ask "what has my child learnt today" and one of the directors commented that she had to think over how to handle the question before answering. The staff sometimes feels unsecure to reply and thus avoid to answer. In connection with the five-year health check at the child health care centres (BVC) the preschool teachers have to complete a formula with data concerning each child's development. It is an evaluation and sometimes the preschool and BVC do not agree. The requirement of documentation is inserted in the curriculum. The directors argue that much of the documentation in preschool is based on photos and notes on what the children say in different learning situations, but "what will the documentation result in" said one of the directors and the others agreed.

Quality for promoting child development and learning

Quality is a concept often used without deeper thoughts. Most people interpret quality as an expression for "good" quality. However, it is not evident or agreed upon what the concept quality really means as it is rather subjective. Does a higher quality in preschool automatically lead to a higher degree of wellbeing in the children? Probably not. The definition of the concept differs depending on the person who has the power to define it. One measure of quality in preschool can be how satisfied the children and the parents are with the preschool, another how the goals in the curriculum are attained. Also other measures can be used. Often self-reporting scales are used but the preschool directors argue that it is often difficult as it may be critical to evaluate your own activities. When the staff has children's learning and development in focus, when they observe, document and analyse the child, the quality may be visible and observable. If the staff has created environments that many children choose and that a creative activity takes place – this may be a measure of quality. The child group mirrors in different ways what quality is, the directors state. They have difficulties to express what they really mean when they are asked to explain this issue further.

One of the directors pointed out that when several preschool teachers are involved in the activity it is provided that a higher quality is obtained but she says that this is not based on fact. Quality is about value and attitudes and that the staff is working preventive against insults and conflicts. Quality work is influenced by a shortage of competent staff, if the communication between preschool staff and leaders are negative, lack of time for planning, high staff instability, the size of the preschool and the size and compilation of the staff.

DISCUSSION

The view on children, child development, childhood, play and learning has changed during the last centuries. Children are today regarded as social, competent actors in a globalized world and their parents demand care and preschool of high quality (1). At the same time research has shown that the preschool period is of utmost importance in children's lives and growth as their development is optimal during this period (11, 17, 22, 32). The preschool directors in our study argue that focus on quality work, documentation, visualisation of the activities and visualisation of children's learning has increased. It appears that they are critical to how the documentation is used today as they cannot see what it results in. The preschool directors stress that it is the activity that should be evaluated not the single child but in order to be able to evaluate the activity, children's learning and development need to be analyzed first. It is both complicated and contradictory but important that the staff of the preschool learn how to handle this problem from the perspective of lifelong learning but also to connect it to future results in school as for instance pointed out by Wilson (2). This is extremely important for children's health. One question is how to give children in need of special support what they need to promote development if an intervention has not been conducted. A qualified assessment is necessary in order to give these children equal opportunities as other children (24, 29).

When the children are happy and show that they enjoy preschool, can we be sure that this is a sign of quality or is it possible to conclude that the quality is high and that this preschool has succeeded with the pedagogical activity? Not a matter of fact. An activity can be joyful for the children even if it from adult perspective may have low quality. It is a question of focus and whose focus that is the most important (8). From the CRC it appears that the child's voice should be heard and the right to influence their own situation should be respected. But when it comes to preschool it is not evident that the children have opportunities to influence everyday life. Another aspect is the child's right to play and as play is vital for young children's development time for playing need to be extended. Play and learning are closely connected as many researchers have pointed out. What all agree on is that competence and well education staff is necessary in preschool and the directors point out that both preschool teachers and child care workers are needed resources. They have somewhat different competencies but in order to meet the needs of all children for care and learning and to raise the quality in preschool both professional groups are needed. Preschool must be joyful, secure and instructive. Furthermore, research show that preschools with high quality influence children's future schooling in a positive way, a factor that we must considered and not neglected.

CONCLUSION

Does a good quality in preschool contribute to children's health and wellbeing? Many factors influence a high quality in preschool and we have in this article discussed some of these. Our study has confirmed that a good quality in preschool supports children's health and wellbeing. Children who spend most of their waken time in preschool have the right to an activity that has children's best, children's interest and needs in focus. If the preschool takes that into consideration and if the child gets opportunities to participate, to feel secure, is respected and has influence on his/her daily life the preschool will contribute to the child's health and wellbeing. In order to give all children equal good opportunities in preschool it is necessary to raise the quality in preschool by conducting a systematic quality work. A future research question is to exert how much preschool in reality support and compensate children in need of special support or children from disadvantages environments.

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Chapter 16

ACCEPTANCE OF A CHILD WITH A FACIAL SCAR

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In this chapter we examine middle school aged children's ratings of liking, their desire to participate in social activities and their desire to help a child with a facial scar. Results of a multivariate analysis of covariance indicated that females provided higher ratings of liking and desire to participate in social activities and help a child, irrespective of whether the child had a scar, compared to males. Children also provided higher ratings for wanting to help a child with a facial scar than a child without a scar. Findings of the present study suggested that middle school age children were accepting of a child with a facial scar. Future research should examine children's interactions with children who have scars and more severe conditions, such as craniofacial anomalies.

INTRODUCTION

Children who have facial disfigurements may be stared at, teased, ridiculed, targeted by bullies and face isolation (1, 2). Leonard and colleagues reported that children with visible disfigurements were less popular than peers who do not have disfigurements (3). Similarly, children with a visible impairment, such as a facial scar, may be stigmatized or avoided by peers and may be at risk for low social acceptance (4). While these reactions often arise from peers' curiosity, the experience may still be "hostile, intrusive and unwelcome" for a child with a disfigurement (4). This study examined middle school aged children's acceptance of a child with a facial scar. Children were randomly assigned to view a child with or without a scar and then provide ratings of their impressions of the child on several questions. One goal

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was to assess whether children provided higher acceptance ratings for a line drawing of a child without the facial scar than for a child with a facial scar.

In a recent study, Nabors and others used line-drawings to examine several factors, such as characteristics of the perceiver, on elementary age children's attitudes toward a child with a facial scar (5). Findings confirmed that girls typically provided higher acceptance ratings than boys of a same-sex child with a facial scar. In contrast, other studies have indicated that girls react more negatively to and may be less accepting of a child with a facial disfigurement compared to boys (6, 7). Another goal of the present study was to examine the influence of gender on middle school age children's acceptance of a child with a facial scar. It was predicted that a significant main effect would be found for gender, such that girls would provide higher acceptance ratings than boys irrespective of whether the line drawing depicts a child with or without a facial scar (5). Children responded to questions examining their desire to engage in social activities, general liking, and desire to help the child in the drawing.

The reasons for selecting these types of questions are supported in the literature. For example, it is important to investigate children's opinions across different types of social activities, as the type of setting in which an interaction occurs can influence children's acceptance of peers who are physically different (8). We selected two questions about social contexts – going to a movie or a party with the child in the drawing – to assess whether the children would provide positive or negative ratings for interacting with the child. A question about whether children liked the child in the drawing was utilized, in order to examine general levels of acceptance for the child (5). The final question was about wanting to help the child depicted in the drawing. A literature search for this study revealed no information on children's opinions about wanting to help a child who had a facial scar. Researchers examining adults' perceptions found that adults were less likely to help a person with a facial scar compared to a person with no scar (9). Samerotte and Harris suggested that the unattractiveness of the facial scar may have counteracted any sympathetic feelings and caused avoidance of the person with the disfiguring condition (9). We were not certain if this type of finding would be replicated with children and thus were interested in inquiring about children's desire to help those with facial differences.

OUR STUDY

Two hundred and seventy- three children participated in the study (116 males and 157 females). Ages ranged from 10 to 14 years old (M = 12.18, SD = 1.10). Two hundred and thirty-six were Caucasian and 37 were African American. Children were recruited from six public and private middle schools in or nearby a Midwestern city. Parental consent and child assent were required for the children's participation in the study. This study was approved by a university-based institutional review board.

Black and white line drawings of a child with or without a facial scar were used. These drawings have been used to examine children's acceptance in previous research (5). Line drawings were matched for gender and ethnic group of the child answering the questions. Computer generated line drawings were used to control for the physical attractiveness of the models in the drawings, because attractiveness may influence judgments of children in the age range for our sample (10).

Children were randomly assigned to view a line drawing of a child with or without a facial disfigurement. After viewing the drawing, children responded to questions on 7-point Likert scales ("1" = no acceptance and "7" indicating high acceptance) that addressed how much the child liked and wanted to help the child depicted by line drawing and how much they would like to go to a movie or party with the child depicted in the line drawing. The children were instructed that there were no right or wrong answers to the questions and were asked to give their honest opinion when providing answers. After they finished responding to questions, they were asked not to discuss their answers with other children.

FINDINGS

A multivariate analysis of covariance (MANCOVA) was used to examine the effect of gender and the type of line-drawing, facial scar versus no facial scar, on children's ratings for liking of the depicted child, ratings for wanting to attend a party or a movie with the depicted child and ratings for wanting to help the depicted child. Age and school (school where the child was recruited) were the covariates.

The omnibus test for gender was significant, Wilks' Lambda = .906, F(4, 246) = 6.41, $p < .01$. The effects for the type of line drawing viewed and the interaction term were not significant. The covariates were also not significant.

Gender was significant for the liking question, F(1, 255) = 14.56, $p < .01$; for the question addressing the children's desire to go to a movie with the depicted child, F(1, 255) = 15.85, $p < .01$; for wanting to go to a party with either child, F(1, 255) = 4.76, $p < .05$; and for wanting to help the depicted child, F(1, 255) = 12.81, $p < .01$. As shown in Table 1, girls provided higher ratings compared to boys for all four questions.

The univariate test for the type of line drawing was significant for the helping question; F(1, 255) = 6.05, $p < .05$. Children who viewed the child with a facial scar provided higher ratings of desire to help than those who viewed the child without a scar (see Table 1). No significant differences emerged for the other questions. However, the means were higher, indicating higher acceptance, for the child with the facial scar compared to the child without the scar for each of the questions (see Table 1).

Table 1. Means for dependent variables by gender and line drawing condition

Dependent Variable/ Question	Gender				Line Drawing			
	Girls		Boys		Facial Scar		No Scar	
	M	SD	M	SD	M	SD	M	SD
Liking[a]	4.31	1.42	3.58	1.53	4.03	1.47	3.98	1.55
Movie[a]	4.06	1.57	3.22	1.76	3.80	1.79	3.61	1.62
Party[a]	3.81	1.67	3.34	1.65	3.71	1.70	3.52	1.65
Help[a,b]	5.38	1.38	4.76	1.45	5.33	1.49	4.90	1.37

Note. [a] Significant difference between girls and boys. [b] Significant difference between line-drawings depicting scar and no scar conditions.

DISCUSSION

Results of this study suggested that middle school age children were accepting of a child with a facial scar. Consequently, it may be that reactions of peers do arise from curiosity rather than feelings of dislike leading to social stigma (2). Ratings for the child with and without a scar were in the average range of acceptance, and if a difference occurred, it typically favored the child with a scar. Similar to findings of other research, girls typically provided higher acceptance ratings of the child with a facial scar than boys did (5). But, they also provided higher ratings of the child without a scar, indicating that they might in general provide higher acceptance ratings compared to boys.

Interestingly, children provided higher ratings for wanting to help a child with a facial scar than one without a scar. This finding contradicts previous research with adults that suggested individuals are less likely to help those who are disfigured (9). It is possible that children felt increased sympathy and caring which resulted in their desire to help the child. Post hoc correlation analyses indicated that having a desire to help the child was related to the other dependent variables of interest irrespective of whether the child had a scar or not (see Table 2).

Thus, having a desire to help was related to higher ratings on all questions. This is an important area to elaborate on in future studies. Questioning children as to what type of help they think the child needs may provide information to understand why they were more willing to help the child who had a scar.

Several factors limited the generalizability of the study findings. For instance, the line drawings were computer generated and may not have been realistic. Future investigations should use more realistic examples, like photographs or video recordings of children who have scars, to see if these stimuli have the same effect on children's acceptance. Moreover, children in the study sample were predominantly Causasian and the age range was limited. Recruiting a more diverse sample across a broader age range (e.g., older adolescents) may yield different results.

The present study examined children's reactions to only two specific activities, going to the movies and a party. Future research needs to focus on different social contexts since type of setting can have an influence on the acceptance of those with physical differences (8). Researchers may want to investigate children's opinions for other social contexts such as interactions at school, coming to one's home and going on a date.

Table 2. Post hoc correlations for helping, liking and desire to participate in social activities questions for children

	Liking	Desire to Go to a Movie	Desire to Go to a Party
Helping a Child with a Scar (*n* = 134)	0.476**	0.401**	0.497**
Helping a Child without a Scar (*n* = 132)	0.327**	0.321**	0.193*

Note. ** Correlation is significant at the 0.01 level (2- tailed). * Correlation is significant at the 0.05 level (2- tailed). Correlations are for children viewing drawings of a child with and without a facial scar.

Study findings provided preliminary evidence that children who are developing typically are accepting of children with facial scars. As mentioned, it may be that curiosity drives children's questions and reactions rather than negative views of a facial scar. On the other hand, children in this study may have been affected by a social desirability bias when responding to questions. Measures for assessing this response tendency should be included in subsequent studies. Recording conversations between children with and without scars may provide data to determine whether curiosity or some other motive drives interactions among children and peers who have scars. This type of research may show that children do ask questions in a manner that makes the child with a scar uncomfortable. Observing interactions between these children will determine whether children with scars do react to questions in a defensive way and interpret questions as being hostile or intrusive (2). It also will be important to examine whether children hold more negative opinions of more significant impairments, such as cleft lip or palate. Then, designing interventions to assist children in asking questions and also teaching children with scars and other facial anomalies to expect and answer questions about the facial differences will promote understanding and interaction rather than distancing children from one another.

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Chapter 17

SOCIAL BENEFITS FROM SKATEBOARDING IN SKATE-PARKS

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Social capital support and a sense of connection with place are recognised components of human wellbeing. This chapter examines the social capital support health benefits to be derived from skateboarding in skate-parks. A content analysis of 35 skateboarders' survey responses revealed the existence of four benefits, namely, establishing new and reconnecting with old friendships; bonding to a friendship group, gaining peer respect and status; and increased opportunities to interact with people. Collectively, these benefits expanded the skateboarders' social horizons by providing increased opportunities to gain community recognition and acceptance. The implications for planning integrated communities through enhancing skateboarding opportunities are discussed.

INTRODUCTION

The emergence of alternative sports (e.g., skateboarding, kite/surfing, climbing etc) has seen an ideological change in the sports values of many Australians. This has led to a shift in the way that a growing number of adolescents, young adults and some older adults 'do' sports, which in turn has increased the numbers of individuals taking up 'lifestyle sports' (i.e., sports that reflect both the characteristics of the sport and the partaker's desired social identity)(1). This shift to more individualized sporting activities that are conducted under a subcultural group banner has allowed participants to set personal goals that are consistent both with their

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own personal style and their desired social identity. To foster greater understanding of these goals this study presents the perspectives of skateboarders on the social capital support health benefits to be had from engaging in skateboarding and the role skate-parks play fulfil in facilitating their emotional wellbeing.

The psychosocial health benefits to be derived from being part of a bonded friendship network

Health and quality of life issues are known to be enhanced when social interactions occur between an individual's daily living, work and recreational activities (2). For these connections enhance the social capital support resources (i.e., a shared congenial sense of connected belonging, information sharing, practical assistance, problem appraisal, peer affirmation and group identification) that are available to them (3-4). In this regard, it is reasoned that the solidarity and trust which forms between groups of individuals who have overlapping connections is the 'glue' which bonds social networks together as it enables the group's membership to feel both accepted and valued (5). The social health benefits to be derived from bonded social networks are considered to be especially critical for young people in the adolescent identity-seeking stage of their development. For, it is during this time that they have limited independent transport opportunities to expand their friendship networks outside of their immediate neighbourhood confines (6).

A further benefit of belonging to a social network is that the act of socializing with the network's membership mitigates life stress. This typically occurs through members sharing their coping strategies, which in turn helps build resilience (12) as the process of members' providing each other with emotional support not only bolsters individual member's sense of esteem, self-worth, purpose, and security, but also enhances the solidarity of the group (4). Indeed, it is purported that interpersonal involvement with friendship networks raises members' spirits and cements their within-group sense of belonging, place, and community (5-8). Maslow (9) in his hierarchical theory of human need, ranked the development of a sense of belonging as being the third highest human need, placing it only above basic physiological (e.g., breathing, food, water, sex, sleep, homeostasis and excretions) and safety needs (i.e., security). In addition, Hagerty and colleagues (10) have described a sense of belonging as being the basic human desire for recognition and acceptance by members of a desired friendship group. Characteristically, this sense of belonging occurs when new members perceive that they have become an integral part of their targeted group.

More recently still, research has determined that the human sense of belonging is a vital component of healthy psychosocial functioning as it facilitates the establishment and maintenance of friendships over time (11). In this regard, a growing body of research has emerged which clearly demonstrates that individuals with strong friendship networks have fewer somatic complaints, lower levels of anxiety, insomnia, depression and suicide ideation (12-13). However, it is cautioned that these health benefits are proportional to the amount of time network members spend interacting with each other, as the more time spent together the greater the sense of belonging that members form with the group and the greater identification with the group's lifestyle choices (8). The amount of satisfaction members derive from identifying with and being accepted into a group also influences their motivational drive to remaining affiliated with the group and to also live up to the participation expectations of the group.

Social integration benefits to be derived from establishing a sense of place within a community

A social network's identification with a particular public space not only facilitates face-to-face interaction between members by providing them with a place to socialize, but it also provides opportunities for intra-group networking and interactions with the wider community (34). In this regard, the provision of designated public spaces for specific socialization/recreational activities helps foster the physical health and emotional wellbeing of the space users as it provides a physical meeting venue for other interactions with similarly minded people (35). Arguably, as important as the provision of public socialization/ recreational space is to its targeted users, a major provision benefit is that as public spaces are open to all so in essence they act as a defacto mechanism for improving social cohesion given that they provide the targeted space users with interaction opportunities with the non-targeted local community users. Thus, there are ongoing opportunities for integration. This interaction is not only important for improving cultural tolerance and integration (36), but also for encouraging intergenerational use of the space. In the case of skate-parks this intergenerational usage is noticeable, as formerly they were considered the sole domain of adolescent youth, however, now there is growing anecdotal evidence of their use by toddlers, adults and pensioners (16).

The degree to which a sense of place can be generated for the targeted user as well as integrated space for the general public, is in part, determined by the ability of city planners to create meaningful interaction opportunities (14-17). However, when it comes to the provisioning public space for young people, particularly for young people engaged in unsupervised sporting activities such as skateboarding, then such planning interaction endeavours are often thwart with difficulty as they often engender teenaphobic fear and spark divisive public debate (16). Indeed, Taylor and Marais (17) have shown that city planners frequently have to juggle competing community arguments about the need for such adolescent space, particularly in relation to the potential build of skate-park in a residential area. Typically, the pro-youth hang-out-space lobby will argue that the provision of a skate-park will benefit the community by increasing young people's physical activity levels, reducing their obesity levels and feelings of marginalized anger. In contrast, the anti-skate-park-build lobbyists' will typically counter the health benefit agreement with 'not in my backyard' fear of increased crime claims (6, 18). The present study further helps to inform the 'therapeutic landscape' (i.e., everyday places that provide healing opportunities, see Williams, 2008) sport facility provisioning debate by presenting an analysis of the social health benefits that adolescent, early adult and adult skateboarders perceive they obtain from engaging in the alternative sport of skateboarding.

OUR STUDY

This study employs a three-phase triangulated content analysis research design. Its survey instrument, the Engagement in Skateboarding Health Benefit Questionnaire (ESHBQ) produced both the quantitative and qualitative data used in the content analysis. The analysis occurred over three sequential phases, namely, Phase 1, summative content analysis; Phase 2, conventional content analysis; and Phase 3, directed content analysis. The strength of the design is that it provides a basis for large volumes of data to be examined for trends and patterns, for these patterns to be systematically coded and, then for emergent thematic findings to be interpreted in light of the current body of related literature.

Thirty-five male skateboarders aged between 11-46 years (mean = 18.5 years) participated in the study and had between two months and 38 years (mean = 5.8 years) skateboarding experience. Eighteen of the skateboarders skateboarded every day of the week, four skateboarded six days a week, three skateboarded five days a week, two skateboarded four days a week, four skateboarded three days a week, three skateboarded twice a week and only one skateboarder skateboarded once a week. The average length of their daily skateboarding session was 180 minutes. Nineteen skateboarders (54%) skateboarded predominantly in skate parks, seven (20%) were street skateboarders, five (14%) skateboarded both in skate-parks and on the streets, two (6%) skateboarded at skate parks and on ramps built on their home premises and two skateboarders (6%) did not indicate where they skateboarded.

Survey instrumentation

The Engagement in Skateboarding Health Benefit Questionnaire (ESHBQ) comprised 37 items. The first seven items on the ESHIBQ are demographical in nature. The remaining 30 items relate to aspects of the respondents' social wellbeing, (10 questions), psychological health (10 questions), and physical health (10 questions). Due to the large amount of data generated through the ESHBQ this paper only reports on the skateboarders' responses to the questions relating to their social well-being (see Table 1). Each of the questions gathered distinct data.

Procedure

Permission was sought and received from the Human Ethics Committee of the administering institution. Subsequent to obtaining ethics approval, a sample of 35 skateboarders (11 adolescents, 15 early adults & 9 adults) was sourced online via skateboard related public forums, message boards, and other web based communities. After initial email contact with the first author to indicate a willingness to participate in the study the respondents' were sent the ESHBQ and a consent form. Once completed the de-identified ESHBQ data was entered into an Excel spread-sheet in preparation for analysis.

Table 1. Survey questions relating to skateboarders' social health

Item #	Question Type	Question
1	Demographical	What is your name?
2	Demographical	What is your date of birth?
3	Demographical	What is your main country of residence?
4	Demographical	What is your favourite place to skate? (e.g., skate-parks, streets, both)
5	Demographical	Are you commercially involved in the skateboarding? (i.e., do you earn your living from the skateboarding industry)
6	Demographical	Are your skate shoes provided by a sponsor?
7	Demographical	Approximately what percentage of your family are skaters?
8	Social health	Why do you skate?
9	Social health	What social benefits has skateboarding brought you?
10	Social health	Approximately, what percentage of your friends are skaters?
11	Social health	Do you consider yourself to be a serious skateboarder?
12	Social health	Do others consider you to be a serious skateboarder?
13	Social health	Do you wear skate fashion items (e.g., shoes, tee-shirts etc)
14	Social health	Do you play have skateboarding posters in your home?
15	Social health	Do you read skateboarding magazines? If yes, which ones?
16	Social health	Approximately, how many videos have you seen? (i.e., none, 1-10, 11-50, 51-200, 200-500, 500+)
17	Social health	Approximately, what percentage of your image as a whole represents skateboarding?

Analysis

The central purpose of the research was to systematically examine the content of statements made by skateboarder survey respondents. In this regard, the quantitative data was subjected to frequency count analysis and the qualitative data to thematic content analysis. This latter process allows data to be reduced in a systematic manner. Specifically, the process involved the separation of data into 'knowledge' statements (i.e., factual information), belief statements, and value statements, which are then continually compared and abstracted until their contained similarities and differences emerge.

In the first of the three thematic content analysis phases, namely, the summative content phase, the authors independently identified key words contained within the response dataset and ascribed structural codes to the points of interest they identified (19). During this coding process, handwritten memos were made in the margins of the text so that an audit trail could be generated (20). These codes were cross-checked so as to assure identification consistency. Frequency counts were then conducted on the codes. During the second conventional phase of the analysis these identified coded key words were continually abstracted and refined until contained patterns could be grouped into conceptual sub/themes (20). These sub/themes were cross-checked and continually discussed until interpretive consensus was achieved (19-20). During the third directed content phase of the analysis, the emergent overarching sub/themes were interpreted and discussed in light of the available body of pertinent subculture/

skateboarding literature. Finally, data from the combined three phases were triangulated in the discussion section of the paper to produce suggestions for future research directions.

FINDINGS

The findings are reported under the following three headings: summative content analysis, conventional content analysis and directed content analysis.

Phase 1: Summative content analysis – (keywords)

The 35 skateboarders who completed the ESHBQ provided 62 reasons why they persevered with skateboarding. As can be seen from Table 2, for one it was a means of transport, for another it was his job, two skateboarders stated it was for the physical health benefits to be derived from the activity and two others indicated that it was a means of relieving the leisure-related boredom of having nothing else to do in their daily lives other than to watch television. For nine other skateboarders it provided them with a sense of achievement. They described this achievement in terms of the accomplishment of gaining foot control over a piece of wood, the thrill of making it do what they wanted it to do, the sense of progression from mastering new tricks and, the feeling of not wanting to stop for there were still hundreds more tricks to master. However, the overwhelming reasons given by 26 of the respondents for their continued involvement in skateboarding was the enjoyment they obtained from engaging in the activity. Many of the adolescent skateboarders (i.e., those aged 11-17 years) who wrote about their enjoyment of skateboarding did so in terms of it being a fun, awesome leisure pursuit and of it being their favourite thing to do because sticking a trick in front of mates provided them with an incredible adrenaline rush.

Other adolescents still indicated that their continued involvement in skateboarding was a result of hanging out at the park, mastering tricks and demonstrating their dedication to skateboarding as this brought them to the attention of the ‘park homies.’ The ‘homies’ recognition of the skating image that the adolescents were attempting to portray not only felt cool to the adolescents, but also allowed them to form new and rewarding friendships. More importantly, the adolescents stated that the ‘park homies’ acceptance of them allowed them to claim the prized identity status of a skateboarder.

In comparison, the early adult skateboarders (i.e., those aged 18-25 years) described their continued involvement in skateboarding in terms of it being a challenging hobby that provided them with a creative avenue for self-expression and a constructive means of staying out of trouble. In addition, both the early adult skateboarders and the older adult skateboarders (i.e., those aged 26+ years) indicated that their continued involvement in skateboarding was a result of the sense of inner peace they obtain from skateboarding as it not only allowed them to express themselves, but it also provided them with a means of temporarily escaping their problems and conflicted emotions.

Table 2. Skateboarders' reasons for skateboarding

Reasons	Number of responses	% of total 62 Responses	Sample comments
Alleviates boredom	2	3%	• Because there would be nothing else to do • It's something to do besides watch TV. It gets me and my friends outside doing something for the most part that's productive.
Enjoyment	26	42%	• It's fun. • It keeps me happy. • I enjoy it because it is the best. • Just for fun and a hobby. • Because I love it. • It's a great way to have fun. • Because it is fun and very enjoyable. • It's an adrenaline rush. • Awesome fun.
Sense of achievement	9	14%	• There's always something new to learn. • I like to learn new tricks. • I love it when I land a new trick. • When I learn difficult tricks I love the feeling of progression.
Friendship	8	13%	• It's a great way to hang out with friends. • I like the attention I get... it feels cool. • Skaters are really nice to hang around. • I have lots of friends that also skate.
Inner peace	13	21%	• It helps me relax. • I'm free of my problems. • It's an outlet. • It keeps me sane. • It helps me clear my head • It helps me be myself • It's a way to express myself • It takes you away from everything else in life. • When you're skating nothing else matters, nothing else exists. • It's my bent, my way from reality at times. • It lets me look at the world differently.
Physical health benefits	2	3%	• Its exercise. • For fitness
Transportation	1	2%	• I basically picked it up again after 20 years, because I was looking for an easy way of transportation to use in the centre of the city. It's an active source of transportation that's really fun, especially now that I'm confident to clear obstacles and ollie up and down curbs without thinking.
Employment	1	2%	• It's my job

Phase 2: Conventional content analysis: (sub/theme development)

The thematic conventional content analysis of the written responses to ESHBQ Questions 8-17 details the skateboarders' perceptions of the social capital support health benefits to be derived from continued involvement in skateboarding. The analysis resulted in the emergence of one central theme: Expanding social horizons through peer acceptance and personal identification with the skateboarding subculture image and four subthemes: Establishing new and reconnecting with old friendships; Bonding to new skateboarding friends; Gaining peer respect and status; and Meeting new people. Each of these four subthemes is expanded upon below.

Subtheme 1: Establishing new and reconnecting with old friendships

Ninety-four percent (n = 33) of the skateboarders judged friendship acquisition to be the major social health benefit they derived from their involvement in skateboarding. Of these, the adolescent group of skateboarders revealed that their skateboarding friendships were largely formed through their regular attendance at their local skate-park where the 'park homies' observed them practicing their skateboarding tricks. They revealed that the other skateboarders at the skate-park were generally helpful and encouraging. However, they indicated that it was only through continually demonstrating their desire to land and perfect their tricks that the 'homies' welcoming acknowledgements morphed overtime into skateboarding friendships. They commonly commented:

> Whenever you get to the skate-park everyone socializes and no one is mean to each other. (Skateboarder #6)

> I have made a lot of new friends at the parks. (Skateboarder #16)

Moreover, the early-adult age-group of skateboarders' revealed that approximately half of their current friends were skateboarders. Although, some of these skateboarder friends were long-time 'buddies' who they had grown up skateboarding with, the majority of their new friends were skaters who they had met either skateboarding at their local skate-park or through skateboarding on the streets. Typically they commented thus:

> I've made a lot of new friends that skate because none of my old ones do. I am able to see my new skate friends more often as we live so close and we skate almost every day that it isn't raining. (Skateboarder #20)

In the case of the adult skateboarders who returned to the sport after a long period of abstinence from skateboarding, they indicated that their friendship making experiences bifurcated almost equally two types. The first type being 'old friends' whom they had resumed their skateboarding friendships with as illustrated in the following quote:

> I've got closer to old (skate) friends. (Skateboarder #24)

The second type being the new skateboarder friendships they established with other skateboarders of their age who had similarly returned to skateboarding after a long period of abstinence. One adult skateboarder explained:

> I've found some new friends in the form of meeting a bunch of guys my age, who also picked skating back up some time ago. (Skateboarder #18)

Subtheme 2: Bonding to new skateboarding friends

All three age-groups of skateboarders suggested that skateboarding was a fun way of 'bringing mates together' as skateboarding provided them with a 'shared interest.' Initially, this shared interest provided the basis for their casual conversations. However, over time these casual conversations broadened to such an extent that they felt 'bonded' to their skater mates and were able to talk with them about their personal issues. For example, two skateboarders commented:

> I'm better able to talk to other people who skate and relate to them.
> (Skateboarder #17)
>
> I have a tight bond with the skaters. (Skateboarder #23)

Subtheme 3: Gaining status and peer respect

Acceptance into a skateboarding friendship group along with the practice ability of landing various skateboarding tricks is perceived by the study's adolescent and early adult skateboarders to be the means by which they garner 'skateboarder' sub-cultural status, not only in their own eyes, but importantly also in the eyes of non-skateboarders. Frequency count analysis of the responses to survey Question 11 (Do you consider yourself to be a serious skateboarder?) revealed that skateboarders' identification with the skateboarder image was most evident in the early/adult age group as 88% of that age cohort considered them self to be a serious skateboarder.

Frequency count analysis of survey responses to Question 12 (Do others consider you to be a serious skateboarder?) reveals that 82% of the early-adult skateboarders age-cohort also perceived themselves to be viewed as a serious skateboarder by people outside of the skateboarding subculture. Such skateboarders described their social identification with the skateboarding subculture as follows:

> Identity, is like being part of a like-minded group. (Skateboarder #27)
>
> You are instantly different from everybody else if you skateboard. People are interested in talking about it (skateboarding) because everybody remembers trying to skate as a kid. (Skateboarder #32)

> People are impressed when they watch me skate and they seem to like me more because of it. (Skateboarder, #12)

Interestingly, there was a perception among both the early adult age-groups of skateboarders and the adolescent age-cohort that the conferment of a skateboarding identity by others (both within and outside of the skateboarding community) was a necessary precursor to obtaining the skateboarding 'nirvana,' namely, sponsorship. While, the older adults also identified themselves as 'skateboarders' they indicated that any notion of them ever obtaining sponsorship had long since passed. Instead, they revealed that although they were 'serious about having fun skateboarding' it was only a leisure pastime for them. One adult succinctly summarized this viewpoint when he wrote 'it's not taking me anywhere.'

As can be seen from Table 3 frequency count analysis of questions 13-16 survey responses that once involved in skateboarding, the skateboarders became immersed in the commercial aspect of the subculture with 41% of adolescents, 35% of early adults and 63% of adults having viewed between 11-50 skateboarding videos; 71% of adolescents, 94% of early adults and 100% of adults purchasing skateboarding related clothing; 71% of adolescents 88% of early adults and 75% of adults reading skateboarding magazines; and 43% of adolescents, 88% of early adults and 62% of adults displaying a skateboarding poster in their home. Moreover, in response to survey Question 17 (Approximately what percentage of your image as a whole represents skateboarding?) the adolescent, early adult and adult skateboarders' estimation of their skateboarder image was respectively 57%, 51% and 44%.

Table 3. Skateboarders' interactions with the commercial aspects of the skateboarding subculture

	Adolescents	Early Adults	Adults
Never watch skateboarding videos	29%	12%	12%
Have watched between 1-10 skateboarding videos	14%	14%	0%
Have watched between 11-50 skateboarding videos	**41%**	**35%**	**63%**
Have watched between 51-200 skateboarding videos	0%	24%	25%
Have watched between 201-500 skateboarding videos	14%	12%	0%
Do not wear skateboarding fashion clothing	29%	6%	0%
Wear skateboarding fashion clothing	**71%**	**94%**	**100%**
Do not read skateboarding magazines	29%	12%	25%
Read skateboarding magazines	**71%**	**88%**	**75%**
Do not have a skateboarding poster up in their home	57%	12%	38%
Have a skateboarding poster up in their home	**43%**	**88%**	**62%**

Subtheme 4: Meeting new people

Regardless of age, the final social benefit to be derived from skateboarding from the surveyed skateboarders' perspective was the opportunity it provided them to meet new and interesting people (both inside and outside of the skateboarding culture) as well as the chance to go to new and interesting places that they would not otherwise have had the inclination to visit. They wrote as follows:

> Skateboarding has helped me meet a lot of cool people that I probably would not have met, but for skateboarding. (Skateboarder #25)

> With skateboarding you meet a lot of cool people who don't care what you do or where you come from they're just psyched that you skate. (Skateboarder #27)

> I've travelled to other countries and met new people that I wouldn't have if I didn't skate (Skateboarder #32)

Collectively, the study's central theme: Expanding social horizons through peer acceptance and personal identification with the skateboarding subculture image encapsulated the essence of all four subthemes.

Phase 3: Directed content analysis

One participant response written in relation to question 17 (Approximately, what percentage of your image as a whole represents skateboarding?) succinctly summated that the image he intentionally projected to others was: 'I am a skateboarder!' His pronouncement encapsulates the study's core finding that friendship establishment and identification with the skateboarding sub-culture image are the key social benefits that participants derive from their involvement in skateboarding. These benefits are explored now in relation to the available youth subculture and skateboarding literature.

Having friends, being liked, and being included in a central position within peer network is a defining aspect of an individual's social position (21). As such, peer acceptance is known to play a crucial role in the establishment of friendships and, although, most friendships are based on mutual involvement in social conforming activities conducted with like-minded peers, there is a youthful tendency to engage with others in risk-taking activities that actively challenge the established social norms of behaviour (6). Since its inception, skateboarding has fallen into this rebellious risk-taking category as it has long been associated with the hardcore 'punk' youth cult image (22). It is not surprising then that for many members of the wider community skateboarders are often construed as being a 'public nuisance' or a 'polluting presence.' Additionally, that their skateboarding activities are visibly transgressive, threatening and are the providence of 'freeloading' (i.e., non-contributory) male social deviants who intentionally invade public space (23). This form of demonization of skateboarders and skateboarding has had some negative and positive repercussions for young people. For instance, the negative repercussion being that it has contributed both to the public's teenaphobic distrust of congregations of skateboarders (and young people in general (17). An unintended and positive consequence from the skateboarders' perspective is the demonization of skateboarding and skateboarders has cemented the subculture's 'bad' image making the skater identity a much prized 'reputation enhancing' social identity among youth seeking to obtain a non-conforming (or marginally non-conforming) social identity (16).

A key tenet of Reputation Enhancement Theory is that individuals (of all ages) will go to great lengths to develop and maintain their chosen social identity in the presence of their desired audience (24). The identity seeking and peer-group acceptance processes in males is of particular importance to understanding lifestyle recreational/sporting subcultures given that males tend to interact in larger friendship groups and tend to be more focused on issues of companionship, ownership and control than are females (25). Hence, it is understandable why non-regulated physical sports such as skateboarding are attractive to the male gender (6, 26). What is somewhat paradoxical though is that while skateboarders are predominantly male and, skate-parks by extension are 'male spaces,' the image projected by skateboarders is one of an 'alternative masculinity' (27). Namely, one in which the more traditional male values of aggression, power and competitiveness are replaced by values of personal freedom, self-expression and cooperation (27-28). Indeed, the revelation by the present study's participant skateboarders that skateboarding is a 'fun loving,' creative youth subculture in which members are 'never mean to each other' and just like 'hanging-out, relaxing and socializing with each other' is the polar opposite of the violent rebellious image commonly associated with the skateboarding subculture (27, 29-30). This point is further endorsed by Slee's (28) recent analysis of the skateboarding subculture in which it is revealed that a gentle collaborative understanding exists within the subculture and, that young beginner skateboarders are commonly encouraged to persist with their skateboarding activities by older teenage skaters who, in turn, are mentored by older lifers (aka soul skaters). This gentle helping skateboarding image is also at odds with the tough rebellious image promoted by marketers in their skate fashion apparel, youth magazines and videos. Astutely, marketers have surmised that the non-conforming sub-culture image sells not only to the large skateboarding community, but also to the equally sizeable 'poser' youth community who want to be 'seen' as being nominally 'bad' without actually engaging in the sport (28).

DISCUSSION

This study which examined the social health benefits to be had from engaging in skateboarding is situated within the Social Model of Health, which is focused on delineating activities that promote health and protect against ill-health (31). This health model is situated within the conceptualization of public spaces doubling as therapeutic landscapes which provide their end users with the mental health benefit of establish both a sense of attachment to place and a sense of belonging to a group (36). If, as the present study suggests, the skateboarding subculture is capable of providing its membership (regardless of age) with social capital support resources as well as opportunities for improving their physical and mental health, then clearly it is in society's long term interest to foster the skateboarding subculture's active lifestyle. Indeed, instead of restricting skateboarders to skate-parks it would make sense from a health perspective to actively encourage people to extend their skateboarding activities beyond the skate-park. For instance, swimmers not only swim in pools, but also swim in the sea; cyclists not only cycle in velodromes, but also cycle on cycle-paths/roads; ball players not only perfect their ball handling skills on designated pitches, but also on public reserves; therefore, a case could be made for not designing skateboarding out of the built environment but rather designing it in. Indeed, given the large amount of concrete generally used in the architectural design of any city, there would seem to be no end of possibilities for planners to design 'in' informal opportunities for skateboarding milieus to flourish (31).

A second advantage of providing skateboarders with more opportunities to develop and showcase their sporting talents is that greater public visibility and engagement with skateboarders, particularly young skateboarders would not only increase the community's appreciation of skateboarders' skills, but would also help facilitate the acceptance of the subculture in society. In turn, this would help break down divisions and teenaphobic fears that currently surround new skate-park builds (16). Importantly, by building age and cultural bridges with members of the mainstream community, then tolerance of individuals within the community with different interests and attitudes could be enhanced (34). If this were to occur then a win-win health benefit would ensue solution as more people of all ages would become actively involved in skateboarding and the teenaphobic fears of the local community would be lessened.

Limitations of the study

The present small scale study only reveals the perceptions of responding skateboarders within the skateboarding subculture on the social benefits they perceive can be derived from involvement in skateboarding. As such, it does not reflect the viewpoints of non-responding members of the skateboarding community or the broader population outside of the subculture.

CONCLUSION

This research has demonstrated four social capital support health benefits that can be gained from engaging in the sport of skateboarding, namely, establishing new and reconnecting with old friendships; bonding to skateboarding friendship group; gaining peer respect and status; and increased opportunities to meet new people. Collectively, these benefits demonstrate how skateboarders' social and the general public's acceptance horizons can be expanded by providing both groups with opportunities to interact and engage. Formal (skate-parks) and improvised public spaces clearly provide untapped opportunities for enhancing the psychosocial health of the skateboarding community and the non-skateboarding public through creating bridges of trust and mutual acceptance (34). However, the difficulty in realizing these health gains is embedded in the skateboarding subculture's marketed quasi legal 'bad-boy' image as this generates fear in the vulnerable elements of the population.

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SECTION TWO: PREVENTION

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Chapter 18

INFLUENZA AND VACCINATION

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Influenza spreads around the world in seasonal epidemics, resulting in about three to five million yearly cases of severe illness and about 250,000 to 500,000 yearly deaths. Three influenza pandemics occurred in the last century, each caused by the appearance of a new strain of the virus in humans, which killed tens of millions of people. Annual influenza vaccination is therefore of impotance for all children over 6 months of age. The primary care health worker therefore has an important role in prevention and information to parents, so that vaccination coverage among children will be increased.

INTRODUCTION

Influenza is an infectious disease of birds and mammals caused by RNA viruses of the family orthomyxoviridae. Influenza will cause chills, fever, runny nose, sore throat, muscle pains, headache, coughing, weakness/fatigue and general discomfort.

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Influenza spreads around the world in seasonal epidemics, resulting in about three to five million yearly cases of severe illness and about 250,000 to 500,000 yearly deaths. Three influenza pandemics occurred in the last century, each caused by the appearance of a new strain of the virus in humans, which killed tens of millions of people.

New influenza strains emerge when an existing flu virus spreads to humans from another animal species or when an existing human strain picks up new genes from a virus that usually infects birds or pigs. The last major pandemic was in 2009, when a novel flu strain evolved that combined genes from human, pig, and bird flu A (H1N1). Yearly vaccination is the first and important step in protecting against flu. Flu vaccination can reduce illness, physician visits, missed work, as well as prevent flu-related hospitalizations, complications like pneumonia and deaths.

PEDIATRIC MORTALITY

In the United States influenza-associated pediatric mortality has been a nationally notifiable condition since October 2004. In a recent report (1) from CDC (Centers for Disease Control and Prevention) in Atlanta, Georgia, pediatric death from influence during the period from September 1, 2010, through August 31, 2011 is reported.

There were 115 cases from 33 states. Nearly half of the deaths (46%) occurred in children aged under five years. Of the children who died, 49% had no known Advisory Committee on Immunization Practices (ACIP) defined high-risk medical conditions with 35% who died at home or in the emergency department. Of the 74 children aged over 6 months for whom vaccination data were available, 17 (23%) had been fully vaccinated. ACIP recommends that all children aged over 6 months receive vaccination against influenza annually.

Of the 115 cases, 72 (63%) occurred in males with the majority of cases in non-Hispanic white children (52%), followed by non-Hispanic black (18%) and Hispanic (15%) children. The highest numbers of deaths occurred in late January and early February 2011. The median age of patients was 6 years, and 53 cases (46%) were in children aged under five years. Seventy-one (62%) of these cases were associated with influenza A virus infection: 30 (26%) 2009 influenza A (H1N1), 21 (18%) influenza A (H3N2), and 20 (18%) influenza A viruses for which the subtype was not determined. The remaining 44 (38%) cases were associated with influenza B virus infections (1).

Nearly half of the children who died (49%) had no known ACIP-defined high-risk medical conditions, 57 (50%) children were reported with medical conditions recognized by ACIP that placed them at increased risk for influenza-related complications, and the medical history of two children was unknown (2%). Of the 57 children with at least one ACIP-defined high-risk condition, 31 (54%) had a neurologic disorder, 17 (30%) had pulmonary disease, 14 (25%) had a chromosomal abnormality or genetic disorder, 11 (19%) had congenital heart disease or other cardiac disease, and 11 (19%) had asthma or reactive airway disease. Obesity was reported in two (4%) of the 57 children.

Twenty children (18%) died outside the hospital, 20 (18%) died in the emergency department and 74 (65%) died in the hospital after admission. Duration of illness ranged from 0 to 57 days with 33 (31%) children who died within three days of illness onset and 69 (65%) died within seven days. When compared with pediatric deaths among children with at least one ACIP-defined high-risk condition, children without high-risk conditions were significantly more likely to die at home or in the emergency department. The median illness duration before death was seven days among children with at least one ACIP-defined high-risk condition and four days among children without a high-risk condition (1).

The most frequent complications reported were radiographically confirmed pneumonia (62%), shock or sepsis (40%), and acute respiratory distress syndrome (34%). Encephalopathy or encephalitis was reported in 12 children (14%). Of the 47 children who received antiviral therapy, three (6%) died in the emergency department, and 44 (94%) died after being admitted to the hospital. All three children who died in the emergency department received oseltamivir. Of the children who died after being admitted to the hospital, 41 received oseltamivir only, two received oseltamivir and zanamivir, and one received zanamivir only (1).

CONCLUSION

The CDC report (1) highlight the importance of annual influenza vaccination for all children over 6 months of age.

Healthy children aged 2-18 years may receive either live, attenuated influenza vaccine (LAIV) or trivalent inactivated influenza vaccine (TIV). Children aged 6-23 months and those aged 2-4 years who have asthma or wheezing, or who have medical conditions that put them at higher risk for influenza complications should receive TIV. Children aged 6 months-8 years who did not receive at least one dose of seasonal influenza vaccine before should receive two doses at least four weeks apart (1).

Primary care health worker therefore have an important role in prevention and information to parents, so that vaccination coverage among children will be increased.

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Chapter 19

CHILDREN WITH AUTISM AND VACCINATIONS

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Parents of children with autism (PCA) are among those most affected by the controversy surrounding supposed links between vaccines and autism. In this chapter we describe the vaccine attitudes of PCA and their association with satisfaction with their child's healthcare provider. Fifty PCA completed questionnaires on vaccine attitudes, exposure to media discussing links between vaccines and autism ('vaccine-autism media'), and satisfaction with their child's healthcare. These characteristics, as well as autism severity and child cognitive functioning, were examined for their correlation with parents' belief that vaccines caused autism and desire to refuse future vaccination. The majority endorsed vaccines as effective and necessary, yet 56% believed they contributed to autism's cause and 16% would discourage others' vaccination. Nearly 80% discussed concerns with their child's provider and felt they were taken seriously. Attitudes were not associated with parents' demographic characteristics or satisfaction with healthcare, but were associated with trust in health institutions, vaccine safety, exposure to vaccine-autism media, and child's lower cognitive functioning. Conclusions: Although parents reported positive communication with providers, doubts about safety and exposure to vaccine-autism media were common. These findings underscore the importance for targeted campaigns addressing PCA's concerns and to mitigate mistrust.

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INTRODUCTION

Despite increasing evidence of genetic causes of autism spectrum disorder (ASD) (1-3) and an authoritative review rejecting a causal association between MMR vaccination and ASD (4), fear that childhood vaccines play a key role in the etiology of ASD persists (5). In fact, a review by Brown and colleagues (6) identified a significant association between parents' belief that vaccines cause autism and lower vaccine uptake. The controversy continues to attract media attention and many parents remain skeptical about the safety of childhood vaccines (7, 8). The issue is particularly salient for parents of children with autism (PCA) and, with an estimated ASD prevalence of one in 88 (9), vaccine uptake among this group could have a substantive impact on public health.

Online surveys of parents involved with autism organizations in the US and Canada revealed that 40% of parents believed that vaccines were among the most significant contributory factors involved in their child's autism (10). Many factors play a role in producing these beliefs, including the temporal proximity of childhood vaccination and the manifestation of autism, distrust of governmental agencies, perceptions of the risks posed by vaccine-preventable diseases (VPDs), and information from popular media sources (11). Several studies have suggested that the latter, especially web-based sources, may fuel distrust in childhood vaccinations (12-15); yet, given limitations in extant research, developing interventions to address these influences would be challenging (16).

Healthcare providers are on the frontlines in the debate about vaccines and autism, and can have a substantial influence on decisions about childhood vaccination (17-21). Therefore, it remains critical that healthcare providers offer information to caregivers, and to PCA, as early after diagnosis as possible (17). The purpose of this study was to examine attitudes toward childhood vaccination among PCA. The association between various dimensions of healthcare satisfaction, vaccine attitudes, and child autism severity and cognitive ability was explored, as was exposure to media sources portraying a link between vaccines and autism.

OUR STUDY

A convenience sample of PCA were recruited through their participation in randomized controlled trials of a parent-teacher consultation intervention in Kentucky and Indiana (22, 23). All children met the diagnostic and statistical manual IV-TR definition of autistic disorder (24) as confirmed by professionally-administered Autism Diagnostic Observation Schedule Modules 1 or 2 (25). Parents (n = 79) were mailed two self-administered surveys assessing their attitudes toward childhood vaccines and their satisfaction with their child's medical care. Fifty parents completed the Parent Satisfaction with Care Questionnaire and 49 completed the Vaccine Attitude Questionnaire (described below). Respondents were not significantly different than non-respondents in terms of child's age, parental education level, income, or race. All study procedures were approved by the University's Institutional Review Board.

Measures

Demographic information including child age, gender, race, household income, number of siblings, and parent education level was collected (described in Table 1). Measures assessing children's severity of autism (Childhood Autism Rating Scale; CARS) and cognitive ability (Differential Abilities Scale; DAS) were administered by the research team (23). The CARS is a valid and reliable, observational scale comprised of 15 items evaluating behaviors such as social relating, resistance to change, communication, and body use (26). The General Conceptual Ability subscore of the DAS, which has strong internal and test-retest reliability (27), was used to assess children's cognitive ability.

Participants also completed questionnaires assessing their satisfaction with their child's primary healthcare provider (PCP); Table 2 provides example items and coefficient alphas for subscales. The 24-item Parent Satisfaction with Care Questionnaire contained seven subscales and was based on a modification of two established measures for assessing individuals' satisfaction with medical care (28, 29). Five subscales examined parents' perceptions of their child's PCP, including his/her informativeness, interpersonal sensitivity, competence to care for a child with autism, and willingness to engage in partnership building with caregiver. Two additional subscales assessed parents' reported accessibility and affordability of healthcare for their child. Response options were arranged on a 4-point Likert scale ranging from strongly agree to strongly disagree.

Parents also completed a 43-item Vaccine Attitude Questionnaire, which was based in part on a study of MMR vaccine attitudes conducted in the United Kingdom (30). The modified questionnaire contained six subscales examining parents' 1) perceived safety and efficacy of childhood vaccines, 2) perceived benefits of childhood vaccination, 3) trust in health institutions such as healthcare providers, the government, and pharmaceutical companies, 4) communication with the child's PCP about vaccination, 5) sense of responsibility to vaccinate their child for his/her welfare and the benefit to society and 6) desire for autonomy in making childhood vaccination decisions. Responses were arranged on a 4-point Likert scale ranging from strongly agree to strongly disagree. Table 3 provides items and coefficient alphas. Likert scale items on both the Parent Satisfaction with Care and Vaccine Attitude Questionnaires were recoded for analysis such that higher values indicated attitudes more positively associated with the subscale construct.

Caregivers were also queried about their exposure to information about links between vaccines and autism. Parents were asked the following three questions: 1) "Have you encountered information on/from [source] about links between vaccines and autism?"; 2) "Was the information useful?"; and 3) "Did the information increase your fears regarding vaccines and autism?" These questions were asked for six different sources (see Figure 1). From these data, a binary variable was created in which caregivers with an affirmative response on the third question for any source were assigned a 1 and their counterparts were assigned a 0.

Outcome measures

Three items on the Vaccine Attitude Questionnaire served as the outcome measures for analysis. Responses to the following three questions were dichotomized (1 = strongly agree/agree; 0 = strongly disagree/disagree): “Vaccines contributed to the cause of my child’s autism,” “I would recommend to others not to vaccinate their children,” and “If there were no penalties for doing so, I would refuse to vaccinate my children.”

Analysis

Subscale scores were computed as an average of item ratings. Bivariate associations between the outcome variables and continuous and categorical correlates were assessed through a series of independent samples t-tests and chi-square tests, respectively.

FINDINGS

Demographic characteristics of the sample are described in Table 1. The majority of the sample was white (68%), 50% reported a family income of greater than $25,000, and 54% of mothers had attended some college. The majority (86%) of children were male. The average age of children was 5.82 (range: 3 to 9); 22% were under the age of 5 years. Most children (70%) had at least one sibling.

Table 3 describes participants’ attitudes toward childhood vaccination. Of note, only 38% believed that childhood vaccines were safe, 30% believed that scientific evidence had shown that vaccines do not cause autism, and 71% reported that they were concerned that their child could get autism from vaccines. However, the majority (89%) did believe that vaccines were effective in preventing disease. Most (92%) believed that VPDs were serious and 88% believed that their children would be at risk for those diseases without vaccination. The majority of parents (72%) also believed that people who do not vaccinate their children put others at risk. Similarly, 84% felt that they had a responsibility to vaccinate their children “for the protection of all children.”

Parents’ trust in regulatory and health-related institutions involved with vaccination was relatively low. For example, only 60% trusted the opinion of their child’s PCP regarding the safety of vaccines, and 47% trusted the pharmaceutical companies producing vaccines. Fewer than half (45%) believed that the government would stop vaccination programs if they were found to be dangerous to children. Despite mistrust, most parents (79%) reported that they did discuss their concerns about vaccination openly with their child’s PCP and 70% reported that their concerns were taken seriously. Most parents valued their autonomy in the vaccine decision process, with 71% reporting that vaccination should be a parental decision rather than one mandated by healthcare providers or the government. Moreover, nearly one-fourth (22%) reported that vaccines should not be mandatory for school attendance.

Figure 1 describes parents’ exposure to information about the vaccine-autism controversy. The most common source was the internet (reported by 88%), followed by television, magazines, newspaper, parent support groups, and healthcare providers. The majority of parents reported that the information they obtained was useful, ranging from 65% of those receiving information from healthcare providers to 77% for that from parent support groups. Except for those who acquired information from a healthcare provider, the majority of parents reported that the information increased their fears about the association between vaccines and autism. Information obtained from parent support groups provoked fear among proportionally more parents (71%) than did television (70%), internet (67%), magazines (63%), and newspapers (60%). Of note, among those encountering information from healthcare providers, comparatively fewer (37%) reported an increased fear of the links between vaccines and autism.

Over half (56%) of the parents believed that vaccines had contributed to the cause of their child's autism, 30% reported that they would refuse to vaccinate their children if there were no penalties for doing so, and 16% reported that they would recommend others not to vaccinate their children. Most parents (71%) believed that vaccines given later in childhood were less likely to cause autism than those given to children at a younger age and 60% believed that vaccines involving doses that were weeks or months apart were less likely to cause autism than vaccines given all that once.

Bivariate analyses

Table 1 presents results from bivariate analyses. Due to the low number (n=8) of participants who reported that they would recommend others not to vaccinate their children, this variable was not included as an outcome in analyses.

Demographic characteristics and satisfaction with care. None of the demographic variables, including parent education level or child's autism severity, were associated with beliefs of vaccines as a cause of autism or refusal to vaccinate if no penalties existed. Of note, characteristics related to parents' perceptions of their child's PCP and accessibility/affordability of medical care were not significantly associated with parents' belief that vaccines had contributed to their child's autism or to their desire to refuse vaccination.

Belief that vaccines contributed to child's autism. Parents who believed that vaccines had contributed to the cause of their child's autism were significantly more likely to report that they had encountered media that caused them to have fear about the possible links between vaccines and autism ($p < 0.001$). These parents had lower average ratings on subscales assessing perceived vaccine safety and efficacy ($p < 0.001$), negative consequences of non-vaccination ($p = 0.008$), trust in healthcare institutions ($p < 0.001$), and sense of responsibility to vaccinate for the welfare of their child and for other children ($p = 0.043$). Parents who believed vaccines had contributed to the cause of their child's autism also believed that parents should have more autonomy in childhood vaccination decisions ($p = 0.036$). Child autism severity nor child cognitive ability were significantly associated with parents' belief that vaccines had contributed to their child's autism.

Desire to refuse vaccination. Parents who reported that they would refuse to vaccinate their children if there were no penalties for doing so were significantly more likely to report that they had encountered media that caused them to have fear about the possible links between vaccines and autism ($p = 0.017$). These parents had a lower average ratings on subscales assessing perceived vaccine safety and efficacy ($p = 0.002$), lesser trust in healthcare institutions ($p = 0.043$), and believed that parents should have more autonomy in childhood vaccination decisions ($p = 0.004$). Parents who reported that they would refuse to vaccinate their children if there were no penalties for doing so had children with significantly lower DAS scores; however, autism severity was not significantly associated.

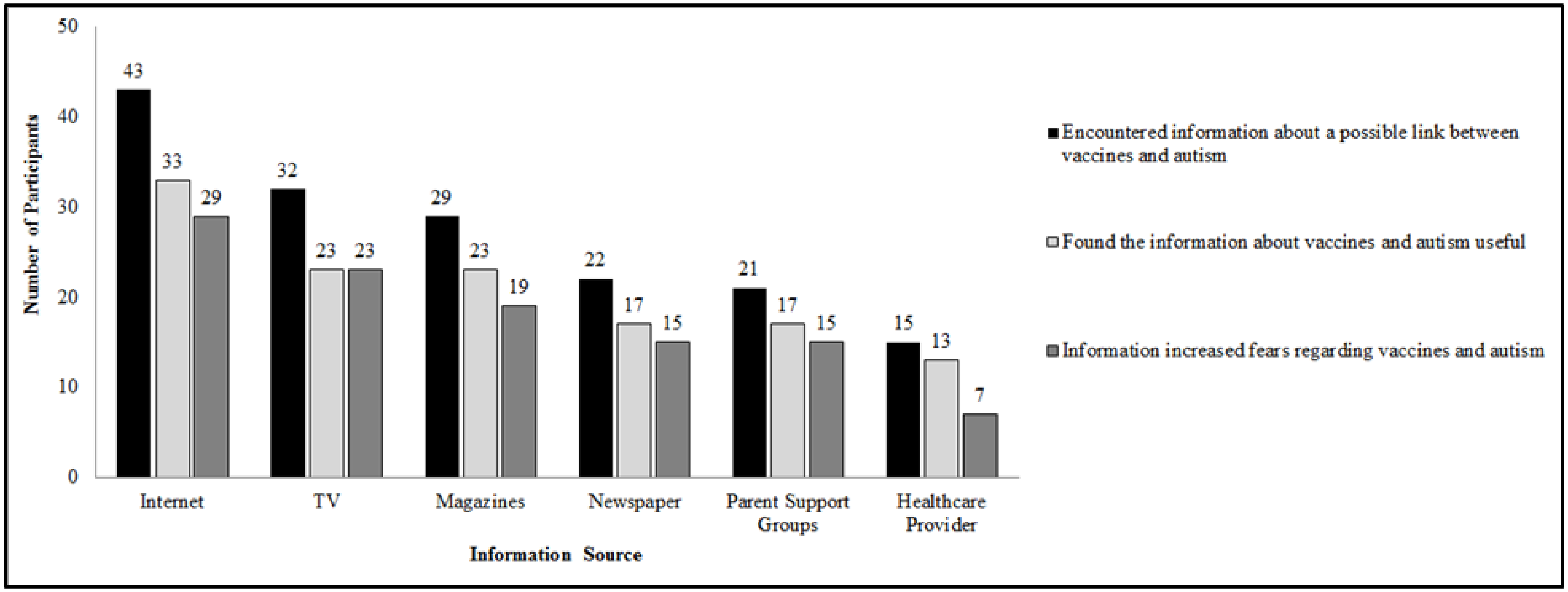

Figure 1. Caregivers' exposure to information regarding a link between vaccines and autism.

Table 1. Bivariate analyses of parents' (n=50) beliefs toward childhood vaccination and experiences with child's healthcare provider

Correlate	Total	Vaccines contributed to cause of child’s autism. (n = 43)			Would refuse to vaccinate if there were no penalties. (n = 47)		
	mean (SD)	Disagree mean (SD)	Agree mean (SD)	p-value	Disagree mean (SD)	Agree mean (SD)	p-value
Demographic and ASD-related characteristics							
White – n (%) (n = 47)	34 (68.0)	11 (57.9)	18 (81.8)	0.168	28 (71.8)	6 (85.7)	0.657
Mother attended college – n (%) (n = 41)[a]	27 (54.0)	10 (66.7)	13 (65.0)	1.000	21 (61.8)	5 (83.3)	0.399
Income greater than $25,000 – n (%) (n = 39)[b]	25 (50.0)	6 (46.2)	15 (75.0)	0.142	20 (62.5)	4 (66.7)	1.000
Child's gender (male) - n (%)	43 (86.0)	17 (89.5)	22 (91.7)	0.806	35 (85.4)	7 (87.5)	0.875
Child's age	5.8 (1.6)	5.4 (1.6)	6.2 (1.6)	0.115	5.8 (1.6)	5.8 (1.7)	0.991
Number of siblings (n = 47)	1.2 (1.1)	1.3 (1.3)	1.1 (1.1)	0.625	1.4 (1.1)	0.6 (1.2)	0.094
CARS Score (n = 48)	37.7 (8.5)	39.4 (8.4)	37.3 (9.1)	0.455	36.9 (9.0)	41.3 (6.0)	0.194
DAS Score	47.6 (21.2)	50.0 (24.4)	47.3 (20.5)	0.696	51.1 (21.2)	32.8 (13.9)	0.024*
Vaccine Attitudes							
Perception of vaccine safety/efficacy	2.0 (0.5)	2.5 (0.4)	1.8 (0.4)	<0.001†	2.2 (0.5)	1.7 (0.3)	0.002†
Negative consequences of non-vaccination	3.1 (0.5)	3.3 (0.5)	2.9 (0.5)	0.008†	3.2 (0.5)	2.8 (0.7)	0.102
Trust in health institutions	2.3 (0.7)	2.8 (0.6)	2.0 (0.5)	<0.001†	2.4 (0.6)	2.0 (0.7)	0.043*
Vaccine communication with PCP	3.0 (0.7)	3.1 (0.7)	3.0 (0.7)	0.860	3.0 (0.6)	3.0 (0.8)	0.873
Desired autonomy	2.5 (0.7)	2.3 (0.7)	2.8 (0.7)	0.036*	2.4 (0.6)	3.0 (0.6)	0.004†
Sense of responsibility to vaccinate	3.1 (0.6)	3.3 (0.6)	2.9 (0.6)	0.043*	3.2 (0.5)	2.9 (0.7)	0.058
Satisfaction with medical care							
Physician informativeness	2.9 (0.7)	2.9 (0.6)	2.9 (0.8)	0.788	2.9 (0.7)	2.9 (0.7)	0.927
Interpersonal sensitivity	3.2 (0.6)	3.3 (0.6)	3.3 (0.5)	0.864	3.2 (0.5)	3.3 (0.5)	0.875
Partnership building	2.9 (0.6)	3.0 (0.7)	3.1 (0.6)	0.691	3.0 (0.6)	3.0 (0.6)	0.846
Perceived competence	2.7 (0.7)	2.7 (0.7)	2.8 (0.7)	0.584	2.7 (0.7)	2.6 (0.7)	0.730
Accessibility of care	2.9 (0.5)	3.0 (0.5)	3.0 (0.6)	0.720	2.9 (0.5)	2.8 (0.6)	0.343
Affordability of care	2.8 (0.6)	3.1 (0.7)	2.7 (0.6)	0.065	3.0 (0.6)	2.6 (0.7)	0.126
Encountered information provoking fear about vaccine-autism link - n (%)	32 (65.3)	5 (27.8)	22 (91.7)	<0.001†	18 (54.5)	13 (92.9)	0.017*

SD: standard deviation, ASD: Autism Spectrum Disorder, CARS: Childhood Autism Rating Scale, DAS: Differential Ability Scales, PCP: Primary Care Provider

*$p < 0.05$, $^{\dagger}p < 0.01$. [a] Response options for parents’ education-level included, *“graduate/professional training,”“college graduate,” “some college,” “high school/general equivalence degree,” “some high school,” “junior high school,”* and *“less than 7 years of education.”* Data were dichotomized at the mean (1 = some college or greater, 0 = no college attendance). Given that 50% of respondents reported that father's education level was “not applicable,” mother’s educational attainment was used for analysis. [b] Response options for household income included, “*Less than $10,000,” “$10,000 - $24,999,” “$25,000 - $49,999,” “$50,000 - $100,000,”* and *“Greater than $100,000.”* Data were dichotomized (1= $25,000 or greater, 0 = Less than $25,000) at the mean and to closely correspond with the US Federal Poverty Level for a four person household (US Department of Health and Human Services, 2013).

Table 2. Description and internal consistency of subscales within the Parent Satisfaction with Care Scale

Scale	Items	Example Item	Coefficient α
Physician's informativeness	5	The doctor thoroughly explains everything to me.	0.87
Physician’s interpersonal sensitivity	4	The doctor shows a genuine interest in my child’s well-being.	0.81
Physician/caregiver partnership building	4	The doctor asks for my thoughts about autism.	0.80
Physician's Competence	3	The doctor’s office has everything needed to provide complete medical care to a child with autism.	0.79
Accessibility of care	4	I can make doctors’ appointments at a time that is convenient for my schedule.	0.51
Affordability of care	3	I have to pay for more of my child’s medical care than I can afford.	0.71

Table 3. Description and internal consistency of subscales within the Vaccine Attitude Questionnaire

Question	n (%)[a]	Coefficient α[b]
Vaccine safety and efficacy		**0.85**
Childhood vaccines are safe (n = 47)	18 (38.3)	
Childhood vaccines are very effective in preventing disease. (n = 47)	42 (89.4)	
More research is needed to fully investigate the effects of childhood vaccines. (n = 47) [c]	47 (100.0)	
Possible complications of vaccination can be very serious for children. (n = 47) [c]	45 (95.7)	
Scientific evidence has shown that vaccines do not cause autism. (n = 47)	14 (29.8)	
My child getting autism from vaccines is a major concern for me. (n = 49) [c]	35 (71.4)	
Consequences of non-vaccination		**0.83**
The diseases childhood vaccines prevent are serious. (n = 48)	44 (91.7)	
Without vaccines, my child would be at risk for getting the diseases they prevent. (n = 48)	42 (87.5)	
People who do not vaccinate their children put others at risk. (n = 47)	34 (72.3)	
More kids should be vaccinated so that outbreaks do not occur. (n = 48)	32 (66.7)	
Trust in health institutions involved with vaccination		**0.80**
I trust the opinion of my healthcare provider regarding safety of vaccines. (n = 47)	28 (59.6)	
I trust the companies producing my child's vaccines. (n = 47)	22 (46.8)	
The government would stop childhood vaccination programs if they were dangerous to children. (n = 49)	22 (44.9)	
The government is too defensive about childhood vaccines. (n = 48) [c]	35 (47.9)	
Communication about vaccination with healthcare provider		**---**[a]
I discuss my concerns about vaccination openly with my child's healthcare provider. (n = 47)	37 (78.7)	
My concerns about vaccination are taken seriously by my child's healthcare provider. (n = 47)	33 (70.2)	
Desired autonomy in vaccination decision		**---** [a]
Parents should make decisions regarding their child's vaccination rather than healthcare providers or the government. (n = 49)	35 (71.4)	
Vaccines should not be required to attend school. (n = 49)	11 (22.4)	
Sense of parental/societal responsibility to vaccinate		**---** [a]
I have a responsibility to vaccinate my children for the protection of all children. (n = 49)	41 (83.7)	
As a caregiver, I have a responsibility to vaccinate my child for his/her welfare. (n = 49)	45 (91.8)	

[a] Number and percent who indicated that they agreed or strongly agreed with the statement.

[b] Coefficient alpha not computed for scales comprised of fewer than three items.

[c] Items were reverse coded for computation of subscale score and coefficient alpha.

DISCUSSION

Among this sample of PCA, over half believed that vaccines had contributed to the cause of their child's autism, and over 70% reported that they were concerned that a child could get autism from vaccination. Nearly one-third reported that they would refuse to vaccinate their children if there were no penalties for doing so and nearly one in every six parents reported that they would discourage other parents from vaccinating their children. In this sample, nearly 90% believed that vaccines were effective in preventing disease and over 90% believed that the diseases vaccines prevent are serious. Moreover, nearly 88% of parents reported that, without vaccines, VPDs would pose a risk to their children. These findings are similar to those found in previous research (31). Many studies have reported that low perceived risk of VPDs and doubts about vaccine efficacy contribute to negative attitudes toward childhood vaccination (32-34), though there has been some evidence to the contrary (35).

Perceived safety of childhood vaccines was low, with fewer than 40% reporting that vaccines were safe. Parents who believed that vaccines had contributed to the cause of their child's autism and those who would refuse to vaccinate their children if there were no penalties for doing so reported significantly less confidence in vaccine safety and efficacy than did their counterparts. Distrust of health-related institutions responsible for ensuring safety was common, with fewer than half reporting that they trusted the companies producing vaccines and 45% believing that the government would stop an unsafe vaccination program. Parents who believed that vaccines had contributed to their child's autism and those who would refuse vaccination reported significantly less trust in health institutions. Previous research suggests that institutional trust and perceptions of safety are related. Parental trust in the institutions that develop and regulate vaccines may affect information-seeking behavior and how they receive, process, and react to risk communication from those sources, including material insisting upon vaccine safety (36). As such, vaccine promotion activities involving increased dissemination of information from sources perceived as having questionable credibility is likely to have a limited impact on vaccine attitudes, particularly when the material targets parents' risk:benefit calculus and fails to address underlying mistrust (36).

Of note, the majority of parents believed that alterations in the vaccine schedule would improve the safety of vaccines, specifically delaying vaccines until later in childhood and spacing the doses further apart. Similar attitudes have been identified in previous research (18) and national data suggest that delayed vaccination is not uncommon in the United States (37). These beliefs may be indicative of parents' attempt to educate themselves about vaccination and of their exposure to social discourses, advocated by vaccine-resistant groups and others, suggesting a moral imperative for parents to make empowered, informed, and educated decisions about vaccination to protect their children's health (38). Thus, in a sense, vaccine-resistant groups and public health authorities are promoting the same message: individuals should be informed and empowered to take personal responsibility for their health-related decisions. In this quest, however, individuals are exposed to various information sources and often to 'mixed messages' (38).

While the cross-sectional design precludes ability to draw conclusions about the origins of parents' attitudes, it is notable that 65% reported encountering information from popular media sources, parent support groups, and/or healthcare providers that increased their fear about the links between vaccines and autism. Parents who were exposed to information that provoked fears related to vaccines and autism were significantly more likely to report that vaccines had contributed to the cause of their child's autism and that they would refuse to vaccinate their children in the absence of penalties. Healthcare providers were described as the least frequent source eliciting fear, and the internet was the most common source of exposure to information about the controversy over vaccines and autism. These findings are consistent with those of Woo and colleagues (11) who found that information from magazines/newspapers, healthcare providers, and the internet played important roles in parents' suspicion about links between vaccination and their child's autism.

The implications of these findings for public health practice are complex. Parental mistrust in governmental and pharmaceutical institutions undermines these institutions' ability to discredit and/or counteract information from other sources. Moreover, mistrust may motivate parents to seek information from alternative sources, and circularly, information from alternative sources may contribute to further mistrust. Future longitudinal research is needed to unpack details about the temporality and directionality of these associations. Public health authorities' engagement in an 'information war' with other sources will likely be ineffective if content explicitly or implicitly communicates that vaccine resistance is an 'irrational' and/or ignorant miscalculation of risk without addressing trust, uncertainty, parent's personalized concepts of their children's vulnerability, and the social and political contexts in which scientific evidence is produced and vaccine decisions are made (36, 38, 39).

With the exception of information received from healthcare providers, information about autism and vaccination encountered from other sources provoked fear in the majority of those parents exposed to it. Interestingly, proportionally more parents who encountered information about autism and vaccines from parent support groups reported that it provoked fear than those who encountered the information from other sources. Previous research has shown that PCA perceive autism organizations to be an equally credible or more credible source of vaccine information than organizations such as the CDC, National Vaccine Information Center, and American Academy of Pediatrics (11). However, dimensions of trust and attitudes regarding credibility and authority are complex. For example, discourses of vaccine-resistant groups frame 'trusting blindly' in traditional scientific authority as symptomatic of disempowerment and entailing a substantive risk (38). Thus, vaccine promotion efforts aiming to improve public trust in traditional health-related institutions may be misguided if 'trust' is in itself seen by consumers as a risk (38). Of note, the present study did not inquire about the specific type of support groups with which parents were involved. Additional research about the types of organizations with which PCA typically affiliate, as well as informal and/or formal discourses about vaccination within these organizations is needed to more fully understand if and how parents' affiliation with these groups affects vaccination behavior. Furthermmore, researchers and public health practitioners interested in working with and writing about these groups should be thoughtful in how they frame their language. Specifically, previous research cautions against the tendency to identify these groups with an anti-vaccine 'social movement,' as this attribution may inherently grant more social theoretic foundation to their claims by conflating it with broader political transformations focused on individual rights and resistance to authority (40).

Studies have highlighted the important role healthcare providers play in encouraging the uptake of childhood vaccination (17, 30). In fact, a literature review revealed that mistrust in healthcare systems and negative experience communicating healthcare providers about vaccination are often associated with lower vaccine uptake (6). In the present study, the vast majority of parents reported that they discussed their concerns about vaccination with their child's healthcare provider and that the provider took their concerns seriously. On average, parents had positive ratings of their healthcare providers' informativeness, sensitivity, competence, and partnership building. Nevertheless, only 60% reported that they trusted their provider's opinion regarding vaccine safety. This percentage is slightly less than that reported in a recent nationally representative survey of parents (41). Although somewhat low, the level of trust in healthcare providers exceeded that reported for other authorities associated with vaccination (pharmaceutical companies, government, etc); thus, the patient-provider relationship may represent an opportunity for effective dialogue about childhood vaccination. Of note, however, none of the measures related to satisfaction with child's PCP or accessibility and affordability of medical care were significantly associated with vaccine attitude outcomes in this study. Given these findings and the logistical constraints faced by healthcare providers (12), immunization campaigns cannot rely solely on healthcare providers to promote vaccination, but must engage other mobilization activities and/or electronic, visual, and print media channels (41) directed at parents and support groups specifically.

Demographic and ASD-related characteristics were generally not associated with vaccine attitudes, with the exception that children of parents who reported they would refuse vaccination had lower cognitive functioning, as assessed by the DAS. Additional research is needed to investigate factors that mediate the association between childhood cognitive functioning and parents' attitudes toward childhood vaccination. For example, mediators may include differences in timing of diagnosis and appearance of symptoms of regression and/or variations in parents' information-seeking behavior according to child's level of cognitive functioning.

Most parents desired autonomy in vaccine decision-making, but the majority reported that they felt a personal obligation to vaccinate for the protection of others and the child. Parents who believed that vaccines contributed to the cause of their child's autism and those who would refuse vaccination desired significantly more decision-making autonomy than their counterparts. The former also felt significantly less responsibility to vaccinate. Interestingly, the concept of societal responsibility to vaccinate often has been ignored in vaccine promotion materials. Although the public health rationale for mitigating vaccine refusal is to maintain coverage levels necessary to achieve herd immunity, many promotional materials focus on presenting the individual-level risks and benefits of vaccination (36). In the present study, 84% of parents believed that they had a responsibility to vaccinate their children for the protection of all children, and parents' sense of societal responsibility to vaccinate was strongly associated with their vaccine attitudes; these findings highlight a pivotal point to target in vaccine promotion. Public health communications and efforts addressing vaccine uptake among PCA should leverage and include information addressing attitudes surrounding the societal implications of individual-level vaccine uptake.

Nevertheless, the tension between individual autonomy and government regulation in immunization has a long and contentious history in the United States and will be difficult to address (42). Nationally, parents are increasingly seeking nonmedical exemptions for vaccination (43), citing religious, ideological, and/or safety concerns (44, 45). As discussed above, in the public health arena, vaccine refusal is often assumed to be a matter of miscalculated of risk; however, autonomy in the context of social movements involving 'alternative' concepts of health and responsibility (36), empowered decision-making (38), and tendencies toward a more personalized approach to parenting and vaccine decision-making (39) also play a role. In the coming years, these and other significant health-related issues related to vaccine refusal (46-48) will force the public health community, policy makers, and the public to confront questions surrounding boundaries of personal autonomy and societal responsibility (44).

While this study provides important preliminary insights into the vaccine attitudes of PCA, the study is not without limitations. Though they were based on measures used in previous research in other settings, the questionnaires assessing parent satisfaction with care and vaccine attitudes were self-developed for this formative study and are in need of further evaluation and integration with validated measures developed since the commencement of this study (49). Additionally, although demographic differences between survey respondents and non-respondents were not observed, the response rate (63%) does raise concerns of participation bias. The study was based on a convenience sample of parents participating in a separate autism-related study; given that the vaccine attitudes of participating parents may differ from non-participants, the findings should be generalized with caution. The small sample size also resulted in limited statistical power to detect differences in some pairwise comparisons.

CONCLUSION

PCA are at the center of arguably one of the most heated debates surrounding vaccination in recent history (7, 8). The present study highlights the complexity of parents' beliefs about vaccination and underscores the failure of popular narratives dichotomizing attitudes as "pro-vaccine" and "anti-vaccine" to adequately portray nuances. In this study, most parents reported serious concerns about vaccine safety, but the majority viewed vaccines as necessary and effective. Concerns about safety are likely related, in part, to issues of trust, perceived credibility, and exposure to sources of information suggesting a link between vaccines and autism. From a public health perspective, the findings clearly point to a need to reestablish parents' trust in scientific evidence suggesting no link between vaccines and autism and in government-backed immunization programs more generally. This will be an ongoing and tenuous process that should involve transparent and truthful dialogue (50), engage trusted members of the community, and acknowledge the value of parent empowerment and information-seeking.

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Chapter 20

IMMUNIZATIONS AND THE PROTECTION OF OUR CHILDREN

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Immunizations for all citizens of the world should be an important goal of all clinicians including those dealing with children and adolescents in developing and developed countries. Vaccine preventable diseases continue to take a devastating toll on these vulnerable human beings. This article summarizes current concepts of immunizations with the caveat that widespread travel brings many diseases around the globe whether one lives in a tropical or subtropical area or anywhere in the world. After an introduction to vaccinology, this discussion considers individual vaccines and updates progress on maternal immunizations. The current anti-vaccine hysteria, now prevalent in developed countries, threatens to induce an explosion of epidemics of diseases now controlled by vaccinology with significant yet unnecessary and tragic increase in human morbidity and mortality.

INTRODUCTION

Proper immunizations of all children, adolescents, and adults should be a mission of all clinicians (1, 2). Global travel allows easy dispersal of dangerous organisms that can infect and injure persons who have no prior exposure to these microbes and thus, often have limited or no immunity against them. Fortunately, many of these diseases are preventable due to existing vaccines which allow the vaccinated individual to avoid the devastation from a growing list of these vaccine preventable diseases (VPDs).

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After millions of years without protection against these microbes, considerable progress has been made since the historic work of Dr. Edward Jenner (1749-1823) in 1796 against the smallpox virus. Small pox was one of the deadliest epidemics haunting humans, killing over one-third of those infected for thousands of years. One hundred and eighty one years after Dr. Jenner inoculated 8 year old James Phipps with cowpox vaccine in 1796, using what was then called the “Turkish” method, smallpox was eliminated from the world, except for stockpiles of this virus in some countries (3). This monumental achievement in medicine had its beginnings in India in the 800s with oral snake venom experimentation and continued in China in the 1100s. Stimulated by Jenner’s work in 1796, the Spanish government embarked on the world’s first immunization campaign between 1803 to 1813 (4), and improved greatly with scientific progress in immunology and microbiology in the 20th and now 21st centuries.

VACCINE BENEFITS

As a result of such progress, many diseases have been reduced or even eliminated in some parts of the world, and millions of human lives have been saved worldwide because of the successful immunization campaigns of the World Health Organization (WHO) and the U.S. Centers for Disease Control and Prevention (CDC) (5-7). For example, smallpox was still seen in the 1960s and 1970s in Africa and Asia but was eliminated by a WHO smallpox campaign starting in 1967; the last case was reported in 1977 (5, 8). Polio has been eliminated in most parts of the world and in many places, diphtheria and congenital rubella syndrome are rarely seen (9).

The US Center for Disease Control and Prevention (CDC) estimates that between its establishment in 1994 and 2013, the vaccines for children program (VFC) in the United States, will prevent an estimated 322 million illnesses, 21 million hospitalizations, and 732,000 deaths over these childrens’ lifetimes with a net savings of $295 billion in direct costs and $1.38 trillion in total cost to society (10). The Expanded Programme on Immunization (EPI) of WHO, started in 1974, prevents two to three million human deaths annually (11). Increased immunization programs in Mexico have resulted in a 34% decreased in mortality in children under 5 years of age from universal immunization for influenza, rotavirus, and pneumococcus (7).

GLOBAL ISSUES

Experts recommend increased vaccine research in more countries. The Vaccines for Africa Initiative (VACFA), for example, note that half of immunization research in Africa comes from only six countries: South Africa, The Gambia, Nigeria, Senegal, Guinea-Bissau, and Kenya (12). Increased communication is recommended between health decision-makers and researchers to improve research in vaccines as well as improved vaccine implementation to the public in Africa (13). Attention to proper vaccine storage is an important issue. Modern vaccines vials are equipped with a vaccine viral monitor consisting of an image of a square inside a circle and contain heat-sensitive material noting cumulative exposure. Transporting and storing vaccines at the proper temperature is a major global effort which maximizes vaccine efficacy.

Nearly all countries now have immunization programs with dedicated budgets, vaccine safety protocols, and surveillance systems. These programs have gone beyond the WHO original plans to deal with the six classic childhood vaccines: tetanus, diphtheria, pertussis, measles, poliomyelitis, and tuberculosis. The world's infants are now routinely vaccinated against *Haemophilus influenza* type b, hepatitis B, rubella, rotavirus, and *Streptococcus pneumoniae*. Selected countries also have campaigns to provide vaccines for dengue, yellow fever, and epidemic meningococcal meningitis (5). The human papillomavirus vaccine is also offered in some countries for girls between 9 and 12 years of age.

Unfortunately many countries are not reaching the goals of the 2020 Global Vaccine Action Plan (GVAP) adopted at the 65th World Health Assembly in 2012 (Geneva, Switzerland). Global immunization coverage was 5% in 1974 and the 2020 target is to reach at least 90% of the world's population (80% or more in all districts). This goal has been reached in 59 countries in 2012 including some low and middle-income countries (5). Unfortunately one in five children do not receive basic vaccines as recommended by the WHO's Expanded Programme on Immunizations (EPI), now in its 40th year of life-saving efforts. Only one in four children in Ethiopia,are fully immunized, and some parts of this country, as noted in many countries, provide better coverage than others. Efforts to improve vaccination rates among children need to target increased education for the mothers of these children (14). Neglect in covering children with CDC and WHO recommended immunizations remains in some countries as well as sex inequality with regard to vaccination rates (15, 16).

ANTI-VACCINE HYSTERIA

Unfortunately, controversy surrounding vaccines arose as soon as vaccinology began, with a number of people in the 19th century mounting an anti-vaccine campaign. Despite gains in safety and vaccine technology, the anti-vaccine movement remains strong in the 21st century (4, 17). Such controversy has reduced the number of people around the globe who have received immunization against vaccine preventable diseases (VPDs). In the United States a survey of parents published in 2011 noted that 83% had vaccinated their children, 11% were planning on such an action, 5% agree to have their children take some but not all vaccines, and 2% refused to have their children vaccinated (18).

INCOMPLETE IMMUNIZATIONS

In addition to parental refusal, other issues with regard to providing comprehensive coverage of VPDs to the public have continued. Some families do not have access to immunizations because of poverty, others have limited access to clinicians, or have clinicians who do not emphasize the important role that vaccinations play in health care. Despite World Health Organization's (WHO, Geneva, Switzerland) and the CDC guidelines, immunization schedules and recommendations can be vary from country to country. Barriers to full implementation include lack of access to comprehensive preventive health care, vaccinations that were administered at the wrong time, or given at incorrect intervals because of clinician error.

Estimates in the United States note that over 35 million American adolescents are missing one or more recommended vaccinations (19, 20) Some may have been vaccinated at the wrong time or with an incorrect schedule because of error by the busy health care system (21). Sometimes an opportunity to vaccinate an individual is missed because the health care system utilizes incorrect contraindications for vaccinations. Some vaccines (such as hepatitis B and varicella) were not part of the recommended vaccine schedule when current youth or college students were younger; in some cases, immunity has waned from earlier vaccinations (22).

Some of the VPDs considered in this discussion are listed in Table 1. More vaccines are being developed and their safety must be demonstrated to a sometimes skeptical public that may receive the wrong information from the media (8, 23) (www.cdc.gov/od/science.iso/). In this discussion, the immunization schedule used in the United States is considered (24, 25). Specific recommendations and schedules will vary from country to country depending on the issues within that country and the precise recommendations of local public health experts — as for example, in Argentina (26).

Table 1. Available vaccines for preventable diseases (partial list)

1.	Tetanus, Diphtheria, Pertussis (DTaP/Td/Tdap)
2.	Measles, Mumps, Rubella (MMR)
3.	Meningococcal Vaccine (MCV4, MPSV4)
4.	Haemophilus influenza b (Hib)
5.	Human Papillomavirus (HPV)
6.	Hepatitis A vaccine
7.	Hepatitis B vaccine
8.	Varicella vaccine
9.	Influenza vaccine (IIV, LAIV)
10.	Pneumococcal (polysaccharide): PPV23, (conjugate) PCV13
11.	Rotavirus vaccine
12.	Cholera vaccine
13.	Rabies vaccine
14.	Japanese encephalitis vaccine
15.	Typhoid vaccine
16.	Yellow fever vaccine
17.	Lyme disease vaccine

PRECAUTIONS AND CONTRAINDICATIONS

Clinicians should pay close attention to the contraindications or precautions for the use of vaccines (27). Sometimes *precautions* are noted for a person who has a condition in which the vaccine might increase the chance or the severity of an adverse reaction, or compromise the ability of the vaccine to produce immunity. Absolute or permanent *contraindications* are rare and include known anaphylactic reaction to a vaccine or a component of the vaccine. Temporary contraindications include moderate or severe illness; additional contraindications for live, attenuated vaccine include pregnancy and immunosuppressive disorders. Clinicians should note that contraindications do not include low grade fever, upper respiratory infections, ear infections, or mild gastroenteritis.

Consultation with experts may be necessary for immunosuppressive conditions. In general, these vaccines are acceptable for use in those with HIV/AIDS who have an adequate CD4 count (at or over 25%), those with leukemia or other cancers if healthy and 3 to 6 months post-chemotherapy, those taking less than 2 mg/kg/day of corticosteroids, and those prescribed a dose of steroids of 2 or more mg/kg/day if less than 2 weeks duration. If two or more live viral vaccines are needed they should be given at the same time; if one vaccine is missed, they must be, separated by 28 days to avoid possible interference from circulating antibodies to the first vaccine.

ADULT VACCINATIONS

Children are not the only ones at risk for morbidity and mortality from vaccine preventative diseases. Many adults are at considerable risk because of low vaccination rates. For example, the combination of influenza and pneumococcal disease represent the 5th leading cause of death in adults in the U.S. over 65 years of age. Annual adult U.S. mortality statistics include as many as 48,000 deaths (average over 23,000) annually from influenza, 6,000 from hepatitis B, and over 5,000 from invasive pneumococcal disease (20, 25). If clinicians caring for adults to not provide these vaccines, death rates for vulnerable adults will remain high.

FUTURE DEVELOPMENTS

Recent advances in vaccinology include the production of new vaccines and combination vaccines. New products in development include vaccines against cytomegalovirus, herpes simplex virus, *Mycoplasma pneumoniae, Neisseria gonorrhoeae, Chlamydia trachomatis*, malaria, HIV, tuberculosis, and others (28). Unfortunately, Immunization against HIV remains elusive at present (29-33). New vaccine delivery systems are under development including patch vaccines, nasal vaccines, microencapsulation, and use of bioengineered plants. This discussion now turns to providing information on specific vaccines.

POLIO IMMUNIZATION

Infectious poliomyelitis was a public health problem at the turn of the 20th century and with the widespread application of polio immunization there was elimination of this infection from the Western Hemisphere and in the United States in the early 1970s (9). In the United States inactivated polio vaccine (IPV) is given at 2, 4, 6-18 months, and 4-6 years; it is not routinely given at or after age 18 years in the U.S. If a 4th dose is given before age four, a 5th dose is recommended. IPV is found as component in multiple combination vaccines: DTap/IPV/Hib, DTap/IPV/Hep B, and DTaP/IPV. Oral polio vaccine (OPV) continues to be used in some developing countries.

WHO launched a vigorous anti-polio campaign in Africa (Polio Eradication Initiative: “Kick Polio Out of Africa”) from 1993 to 2002 that reduced the number of countries with endemic polio from 34 to 2 (5). However, war and political factors have prevented complete eradication as the virus spreads to countries unable to provide effective polio vaccination (34). In June of 2014, a CDC Health Alert noted that 10 countries had active transmission of wild poliovirus that could spread to other countries via international travel from Pakistan to Afghanistan, Syria to Iraq, and Cameroon to Equatorial Guinea.

WHO recommends at least one dose of inactivated polio vaccine (IPV) as part of routine immunization protocols in order to reduce the possibility of type 2 polio development since Sabin type 2 strains have been withdrawn from oral polio vaccine (OPV) (35). Those travelling to areas with endemic polio must receive polio vaccination, if indicated, based on their current vaccine status (36). With further push of a worldwide polio immunization program, polio can be removed from the world and placed in the same elimination status solely occupied by smallpox (9).

HAEMOPHILUS INFLUENZA B IMMUNIZATION

Haemophilus influenza type b is an encapsulated gram negative coccobacillus. Prior to the availability of the vaccine, it was the leading cause of meningitis in the US and caused a wide range of other infections including bacteremia, pneumonia, cellulitis and epiglottis. The introduction of the Hib conjugate vaccine saw a significant decrease in the cases of invasive Hib disease. The Hib conguate vaccine remains available as a single agent. It is also available in two different combination products: combined with DTaP and IPV (3-dose primary series at 2,4, 6 months with a booster at 12-15 months) (38, or combined with hepatitis B vaccine in another combination vaccine in a three dose plan (primary series at 2 and 4 months with a booster dose at 12-15 months). In countries where the Hib vaccine is not routinely provided, there is an increase in *Hemophilus influenzae* type b infections such as epiglottis and meningitis. It is not routinely recommended to give the Hib vaccine after 59 months of age.

TETANUS IMMUNIZATION

Tetanus (Greek word for *taut* or *stretch*) is caused by the *Clostridium tetani* exotoxin and there are about 40 to 50 cases of tetanus in the United States each year, ranging from a low of 34 in 2004 to a high of 601 in 1948. It is usually found in the elderly adult whose immunization never occurred or was many years in the past. *Clostridium tetani* is a gram-positive, rod-shaped, obligate, anaerobic bacterium that lives in the soil as well as the intestinal tract. It causes the classic tetanus disorder with skeletal muscle spasms and lockjaw in generalized tetanus; other forms include neonatal, local, and cephalic tetanus (39).

Tetanus remains a major etiologic agent in disease and death in developing countries (29). The WHO estimates 59,000 newborns died from neonatal tetanus around the world in 2008 (20). Neonatal tetanus can develop if the mother does not have antibodies to this organism. The mortality rate from tetanus varies between 48% to 75%. The tetanus vaccine was first introduced in the US in 1927 and this tetanus toxoid vaccine develops serum IgG antibodies to prevent tetanus. Protection against this organism is noted with a serum tetanus antitoxin level of 0.1 IU/ml or more as measured by ELISA technology. Coverage for tetanus in pregnant women (including adolescents) can dramatically reduce the incidence of neonatal tetanus in tropical regions (40, 41).

DIPHTHERIA IMMUNIZATION

Diphtheria is caused by the *Corynebacterium diphtheriae* toxin produced by this Gram positive, pleomorphic, facultative, anaerobic bacterium also known as the Klebs-Loffler bacillus. It gains entry into the person via the respiratory tract and induces a severe infection with local inflammatory membrane involvement (pseudomembrane), myocarditis, and distal neuritis. The mortality rate is 10-20% and the highest number of cases recorded in the US was 206,939 in 1921, with 15,520 deaths; between 1980 and 2000 there were 53 cases and only two have been reported in the first part of the 21st century.

The diphtheria toxoid vaccine was introduced in the United States in 1923 and develops both serum IgG and mucosal IgG antibodies to prevent diphtheria. Diphtheria is common in various parts of the world including Latin America and the Caribbean countries. Cases increased dramatically in the USSR after its breakup in 1989; by 1998, there were 200,000 cases with 5,000 deaths (42).

PERTUSSIS IMMUNIZATION

Pertussis is caused by *Bordetella pertussis*, a gram-negative, aerobic, coccobaccillus in which humans are the only hosts (43). It was isolated by the Belgian microbiologist, Jules Bordet, in 1906. It causes a highly contagious infection of the respiratory tract with a classic cough lasting over two weeks and up to 180 days; the classic cough is characterized by coughing paroxysms, post-tussive emesis, and/or a respiratory whoop (44, 45). Pertussis diagnosis is confirmed with a nasopharyngeal swab via culture or polymerase chain reaction (PCR) technology. There are over 300,000 pediatric deaths worldwide each year due to pertussis (44).

The highest number of pertussis cases in the United States was 256,269 in 1934, though the first pertussis vaccine (whole cell vaccine) was developed in the early part of the 20th century. Dr. Louis W Sauer (1885-1980) developed an inactivated whole cell vaccine in the 1920s in Evanston, Illinois, and the Danish scientist, Dr. Thorvald JM Madsen (1870-1957), accomplished the first large scale test of the pertussis vaccine in the Faroe Islands of the North Sea in 1925 (42). In 1942, Pearl Kendrick (1890-1980) produced the first combined DTP vaccine with tetanus toxoid, as well as diphtheria vaccine and an inactivated whole cell pertussis compenent. Before the pertussis vaccine was developed, 10,000 persons were dying each year in the United States from this infection.

Though cases of pertussis and numbers of infant deaths dropped dramatically after widespread use of the DPT vaccine in the United States, anti-vaccine forces launched an assault on this vaccine with a charge that the whole cell pertussis vaccine produced encephalopathy in infants. The power of the media was witnessed by a one-hour television documentary that aired on April 19, 1982, in the Washington, DC area called “DTP: Vaccine Roulette,” it alleged that pertussis vaccine induced severe neurological damage in infants (46) Though these charges were later noted to be spurious, the damage was done and many parents withheld this vaccine from their children leading to increase in pertussis infections and increase in infant deaths (47).

While pertussis infections reached a nadir in 1976 with 1,020 cases in the United States, importation of unvaccinated persons to the US along with a decrease in DTP vaccinations lead to a rise of pertussis cases with over 25,000 reported cases in 2004, and 48,277 in 2012. Cases are often to adolescents and adults who have lost their immunity to this infection. Experts suggest there are over 600,000 cases of pertussis each year in the US, and perhaps over three million (42, 48). Unfortunately adolescents and adults without full immunity to pertussis can transmit this infection to infants, often resulting in severe consequences. Approximately half of infants under one year of age who develop pertussis are hospitalized, one in twenty develops pneumonia, one in 100 develops seizures, and death can occur. In the United States there are 10-20 infant deaths each year, and 195,000 annual deaths worldwide in children.

Pertussis immunity from natural infection or vaccine can begin to wane within a few years after an infection or vaccine dose (including the 5 dose DTaP childhood series) (49). This drop in protection from the natural disease or vaccine may be due to genetic changes in *Bordetella pertussis*, representing an ability that other organisms possess in the evolutionary dance for survival. An inactivated acellular pertussis vaccine was developed by Dr. Yuji Sato in 1981, and an acellular vaccine received FDA approval in 2005. This acellular pertussis technology resulted in the Tdap vaccine that is recommended as a one-time dose for adolescents and adults who need a booster (43, 50-54).

It is important to protect (“cocoon”) young infants by vaccinating those around them until they can complete their own primary pertussis series (55). This includes persons living with an infant less than 12 months of age and health care personnel. Coverage of pregnant females is discussed in the maternal immunization section (*vida infra*). A 2012 study investigating the effectiveness of the pertussis vaccine during a pertussis epidemic noted a range from 95% (92%-97%) in those who were 15 to 47 months of age, to 47% (19%-65%) in those who were 13 to 16 years of age; in this study the incidence of pertussis was higher in the unimmunized versus immunized group (56).

TETANUS/DIPHTHERIA/PERTUSSIS (DTAP/TDAP/TD) IMMUNIZATION

Children are usually protected against tetanus, diphtheria, and pertussis as recommended by the Centers for Disease and Control and the WHO. The CDC recommends that young children receive a combination vaccine which covers all three diseases and is administered in a series of immunizations (DTaP at 2, 4, 6, and 15 to 18 months). Globally the number of children protected from these diseases has increased due to continued efforts to educate physicians, governments, and society.

In 1980 world vaccine coverage for the first dose of diphtheria-tetanus-pertussis vaccine (DTP) was 30%, and 20% for the third dose; it was 88% and 76% respectively in 1990, and 91% and 83% in 2012 (5). The third dose (DTP3) reached 77% in 2010 by 12 months of age, as measured by the WHO African Region and more vaccine research as well as immunization policy implementation in Africa is recommended by experts of the Vaccines for Africa Initiative (VACFA) (12).

The CDC notes that the fourth dose of DTap may be given as soon as 12 months of age if the interval between doses 3 and 4 doses is at least 6 months, and the child is at risk for not returning for a visit at the recommended age of 15 to 18 months. The CDC recommends that a DTaP booster be given at 4 to 6 years of age, and a Tdap booster between 11 and 12 years, usually five years after the primary childhood series. The Td immunization used to be given for the early adolescent booster, but now a combination of all three is recommended in the United States (i.e., Tdap) because of a recent rise in pertussis. After the adolescenct dose, a booster for tetanus and diphtheria (Td) is recommended every 10 years. If one is over 7 years of age and did not receive the recommended primary childhood series, the primary series is started as soon as possible utilizing Tdap for the first dose, and completing the series with Td. A second dose is given 4 weeks after the first, a third primary dose 5 to 12 months later, and then a booster every 10 years.

Children between 7 and 10 years of age who did not complete a DTaP series can receive the Tdap. Those 11-12 years who have received a full DTaP series can receive a Tdap vaccine and those who are 13-18 years of age can receive a Tdap if not given at 11-12 years. Older persons who are due for a tetanus-diphtheria booster can be given a Tdap booster if they have never received one. Only one immunization for all three diseases (Tdap) is recommended after the primary series at this time (37). It is not currently recommended to give more than one lifetime Tdap for males and non-pregnant females.

MEASLES, MUMPS, RUBELLA (MMR) IMMUNIZATION

Measles, mumps, and rubella are well-known contagious viral infections that are spread via the respiratory tract with episodic outbreaks. Measles (rubeola or morbilli) has been described since the 9th century and is caused by a paramyxovirus of the genus Morbillivirus that can lead to major complications and death. Unfortunately 900,000 persons die from measles annually around the world. Two doses of this live viral vaccine (MMR—Edmonston-Enders strain) are given to children with recommendations in the US since 1989; the first one is given at or after 12 months of age (12-15 months) and the second one at 4 to 6 years of age (57).

It can be given between 6 and 11 months if the infant is traveling to or living in an endemic area; this early dose does not count for the recommended two dose series. Children and adolescents given separate MMR doses that are not separated by at least 4 weeks need to get caught up with the two-dose series. Being born before 1957 is not in itself proof of measles immunity for those who might be pregnant; those wishing to become pregnant should have evidence of appropriate measles vaccination or serologic results indicating immunity to measles. Fortunately, measles and rubella are rare in the United States due to the high coverage of children with vaccination.

Failure to vaccinate individuals leads to increase in measles. In 2005, a 17 year old unvaccinated female returned to the U.S. from a visit to Romania; during that time she attended a family gathering of 500 people. After she returned from visiting relatives, 34 cases of measles were confirmed and traced back to her (58). Such examples are increasing because of the failure to immunize among all ages, with an increase in the number and percentage of measles cases in those over age 20.

In 1973, only 3% of the measles cases occurred in those over 19 years of age. This increased to 34% in the year 2000. Measles elimination was declared by the CDC in the United States in 2000 since there was interruption of endemic transmission of measles for the year. Reduction in measles vaccination rates since then has increased the prevalence of this disease, with 222 cases reported in the US in 2011, and 288 cases between January 1, 2014 and May 23, 2014 (59). This is in contrast to over 600 cases in 1996 (one-third of which were in adolescents) and a high of 894,000 in 1941. In order to ensure that measles epidemics do not recur, we should strive for a vaccination rate as close as possible to 100%.

Measles is the leading vaccine-preventable disease studied by researchers in Africa between 1991 and 2010 (12). Failure of the measles vaccine to provide protection can arise from ineffective vaccine cold chain system. A report of Nigeria vaccine effectiveness noted a low, 68.6% sero-conversion rate (60). Failure to maintain a high measles vaccination rate leads to measles epidemics with death in some infected individuals. For example, In 2011 India recorded 36% of global measles deaths that included 28 deaths from a group of 3,670 measles cases (61). There is an increase in post-vaccination seizures for children given delayed versus on time MMR vaccinations in the second year of life; this is increased with MMRV (MMR with varicella vaccine) (62).

College students who leave their countries to study in the U.S. are advised to be fully vaccinated against measles to protect them from a potential outbreak at their university and also prevent them from staring the epidemic (63). Adults born in the United States in 1957 or later can receive one MMR dose while adults who need 2 doses are those at high risk for disease and include health care workers, international travelers, and college students. Though measles has been targeted by the Centers for Disease Control and Prevention for eradication from the United States and beyond, the recent surge has put this goal on hold for now (64, 65).

Rubella

Rubella was reported at its highest level in the US at 57,000 cases in 1969, and vaccination with the MMR vaccine has practically removed it from the U.S. with very few if any cases reported each year; the few cases noted are mostly in adults with no immunity. No endemic rubella cases have been reported in the US since 2009. Unfortunately, rubella cases are seen around the world where vaccination rates are low, leading to over 100,000 rubella cases and 100,000 cases of congenital rubella syndrome (CRS) being reported (66). Congenital rubella syndrome (CRS) is a serious condition in which rubella infection during pregnancy results in an infant with many congenital defects including mental retardation, deafness, cardiac defects, cataracts, encephalitis, and others.

The US had a high of 20,000 CRS cases in the 1964 to 1965 period, and now has none thanks to the official rubella vaccination program that began in the US in 1969. It is a tragic result when an infant is born into the world with CRS when it is a preventable condition. Waiver of the rubella vaccine may be acceptable in a female who may become pregnant and who either has a positive serological test for rubella or has documentation of acceptable vaccination. Ironically, though the MMR vaccine has been falsely linked with an increase in autism, its use has been shown to reduce autism in addition to measles, mump, rubella, and CRS (17, 57, 67).

Mumps

Mumps is caused by a paramyxovirus that can lead to classic parotitis but also orchitis, epididymitis, spontaneous miscarriage, meningitis (usually mild), oophoritis, pancreatitis, and even rare encephalitis. It reached its highest 20th century level in the US at over 152,000 cases in 1968, and vaccination reduced its prevalence to less than 1 case per 1 million population in the early 2000s. The mumps vaccine was introduced in the US in 1976 with one dose and then 2 doses (MMR) as of 1989.

A resurgence of mumps is noted in the US since the early 2000s with over 250 cases per year and a number of outbreaks in many states (68). In 2006 there were 6,500 mumps cases in the middle of the US, with the state of Iowa as the epicenter. The outbreak eventually involved 45 states and the District of Columbia (2). During this epidemic, mumps cases occurred in greater than 2 per 100,000 in eight Midwestern states, with over 6 per 100,000 in those 18 to 24 years of age. In this epidemic, complications included orchitis (9.6%), meningitis (0.5%), encephalitis (0.4%), and deafness (0.4%); 2.1% of these students were hospitalized. Failure for some to have received two MMR vaccinations was the cause for some students, but decreasing immunity to the mumps vaccine may have been the main factor in this epidemic. The vaccine seems to be 80 to 85% effective and thus, vaccine failure, played a part in this outbreak (2, 57).

ANTIVACCINE CONCERNS

Perhaps a much greater problem than limited vaccine failure is the growing movement in the United States and Europe against vaccinations including the MMR vaccine. The movement against vaccines began as soon as vaccinology began with the work of Edward Jenner on smallpox (vida infra) (8). As previously noted, concerns with vaccines over the past two centuries have focused on a myriad of issues such as claims of greater efficacy with natural infection versus vaccination, anger at compulsory vaccine programs, concerns with mercury in vaccines, worries about side effects from vaccines, worries about the low efficacy of vaccines, and others.

The MMR vaccine has been the epicenter of current antivaccine angst due to false claims linking it with causing autism (17) . The first salvo in this current movement was fired by the 1982 television documentary falsely alleging brain damage from the pertussis vaccine (8). Then Bernhard Rimland (1928-2006), a highly respected psychologist in the field of developmental-behavioral disorders (i.e., autism, ADHD, learning disorders, and learning disorders) asserted that the mercury-containing vaccine preservative thimerosal was linked to what he saw was an epidemic rise in autism. In 1965, Dr. Rimland founded the Autism Society of America and shortly thereafter, in 1967 he founded and directed the Autism Research Institute in San Diego, California, USA.

Adding to this belief was the work of Andrew Wakefield who is a medical researcher and surgeon from England, but moved to the United States. In 1998 he authored a highly-publicized study in the well-known medical journal, *Lancet*, claiming a link between the MMR vaccine and what he called “autistic enterocolitis” (69). Though this research was later discredited and his article recalled by the journal that published it, the pebble-in-the-pond effect continued, as increasing numbers of alarmed mothers stopped and/or delayed allowing their children to receive the MMR vaccination resulting in increased numbers of infections such as measles (17, 70-74). The public remains concerned even though science has clearly shown there is no link between autism and vaccines or mercury (75-79).

Even so, the lawsuits continue in the United States, the media continues to pursue such stories, and some choose to ignore the remarkable science of vaccinology as in the past (80-84). Globally cases of death from measles have continued; mortality in some countries is about 1 in 1,000 with about 450 deaths in children each day in sub-Saharan Africa (85). Mumps is increasing and children remain at risk to be born with preventable congenital rubella syndrome estimated, as previously noted, at 100,000 infants per year. This remains a poignant and tragic consequence of the failure to vaccinate and the global anti-vaccine hysteria in developed countries.

> Alice in Alice in Wonderland, 1865:
> If I had a world of my own, everything would be nonsense.
> Nothing would be what it is because everything would be what it isn’t.
> And contrary-wise; what it is it wouldn’t be,
> and what it wouldn’t be, it would. You see?
> (Lewis Carroll [Charles Lutwidge Dodgson])

MENINGOCOCCAL IMMUNIZATION

There are approximately 3,000 meningitis cases of meningitis each year due to *Neisseria meningitidis* in the United States, and it has a mortality rate of 14% in addition to a high risk for complications in the survivors that include deafness, mental retardation, and loss of limbs (86-88). *N. meningitidis* is a leading cause of meningitis and bacterial sepsis in the U.S. and the world, especially among adolescents and young adults. In a 2009 meningococcal epidemic in 14 African countries, there were 88,199 reported (suspected) cases that included 5,352 deaths; this was the highest number of reported since an epidemic in 1996.

Infectious rates can range from 0.5 to 1.3 per 100,000 in the US and 1.4 in selected young adults in a college or university setting (89). Those immunized at 11-12 years of age may have decreased protective immunity when 16 to 21 years of age and thus, a booster dose of the meningococcal immunization is recommended. If a dose is given at 16 years of age or older, a booster is not needed later unless the person remains at high risk for this infection (see Table 2) (90). MCV4 (meningococcal conjugate vaccine: vida infra) contains 48 micrograms of diphtheria toxoid but does not provide any protection against diphtheria.

In the US, most cases of meningococcal infection (98%) are sporadic and 62% involve those over 11 years of age. Thus, a university with 40,000 students in the U.S. can expect one case of invasive meningococcal disease every 1 to 2 years unless these students are protected through meningococcal vaccination (91).

Table 2. Persons at increased N. meningitidis risk

Adolescents and young adults (aged 11 through 21); including living in crowded college dormitory conditions and military recruits
Persons exposed during an acute epidemic or outbreak
Those traveling to Mecca during annual Haij
Those traveling to West Africa or other areas with high rates of infection
Individuals with some conditions that lower immunity
– Functional or anatomical asplenia
– Terminal complement component deficiency
Persons (i.e., microbiologists) working in labs with *N. meningitidis*

Table 2 notes those at high risk for *N. meningitidis* meningitis, including university students in crowded dormitory situations with increased smoking and nasopharyngeal carriage of this microbe (92-98). Those in college who are 21 years of age and younger should have received an MCV4 dose within the past 5 years; if not, they can be given this vaccine. Those who are 22 or older do not need a routine MCV4 vaccination. Meningococcal immunization is recommended for those traveling to high risk areas such as the meningitis belt in Sub-Saharan Africa (97, 98). Those getting an MCV4 for travel only need one primary dose while those with medical indications (i.e., asplenia) need two primary doses, 8 weeks apart.

Two quadrivalent meningococcal polysaccharide-protein conjugate vaccines (MenACWY-D; MenACWY-CRM) are available which are licensed for persons aged 2 through 55 years and provide protection against meningococcal serogroups A, C, W, and Y (99). In 2011 MenACWY-D was also approved for those aged 9 through 23 months in the U.S. since the highest rate of meningococcal disease occurs in children under one year of age. There is also a bivalent meningococcal polysaccharide protein conjugate vaccine providing protection for meningococcal serogroups C and Y added to Haemophilus influenzae type b (Hib-MenCY-TT) licensed for use in children aged 6 weeks to 18 months (100, 101). Finally there is a quadrivalent meningococcal polysaccharide vaccine (MPSV4) licensed for those at or over 56 years of age.

The polysaccharide vaccine produces (MPSV4) a less effective T-cell independent immune response but can be used if the conjugate vaccine is not available and for those at or over age 56. Conjugate vaccine technology was developed in the 1980s and utilizes chemical conjugation to carrier proteins that leads to an induced T-cell dependent response for improved protection against this organism. This vaccine (MVC4) was first licensed by the U.S. Food and Drug Administration (FDA) in 2006. Both the polysaccharide and conjugate meningitis vaccine protect against 4 subtypes: A, C, Y, and W-135. MCV4 is given intramuscularly and MPSV4 is given subcutaneously. Vaccine for the protection from the B subtype is available in some countries outside the US, and serotype B can cause 20% of invasive meningococcemia in the U.S (102).

HUMAN PAPILLOMAVIRUS (HPV) IMMUNIZATION

The human papillomavirus (HPV) is the most common sexually transmitted disease microbe that infects over 20 million individuals in the United States with over 6 million new cases each year (87). Prevalence data for adolescent females can range up to 65%; additionally, up to 75% of new infections are found in those between ages 15 and 24 years. Over half of sexually active persons are infected with at least one subtype of HPV, with over 80% of the exposure occurring before 50 years of age. New infections typically develop soon after sexarche (i.e., onset of coital activity).

Over 100 HPV serotypes are classified including 40 that affect the genitals and 15 that are listed as being oncogenc—particularly types 16,18,31,33, and 45. HPV is a global infection and found throughout the world (103). Chronic HPV infection can lead to cervical cancer with over 10,000 cases diagnosed in adult females each year in the U.S. and over 4000 deaths annually. Globally there are over 250,000 deaths annually from cervical cancer.

HPV-associated cancers in males include oropharyngeal, penile, and anal cancers due to HPV 16 (104-106). There are an estimated 22,000 HPV 16- and HPV 18-associated cancers each year in the United States that include approximately 7,000 HPV 16- and 18-associated cancers in males. In males oropharyngeal cancers increased 1% per year from 1973 to 2007 and 3% per year for anal cancers. There are an estimated 250,000 cases of genital warts each year among sexually active males in the US due primarily to HPV 6 and 11. Males having sex with males have an increased prevalence of HPV types 6, 11, 16, and 18.

The first infection in females usually occurs soon after sexual behavior initiates (sexarche) and infection with more than one HPV type often occurs. Use of condoms is not fully protective and rare genital infection may develop from non-penetrative sexual contact as well as underclothes transmission and even surgical gloves as agents of transmission. Though HPV infection is typically cleared from the female within two years after initial infection, it can become a persistent infection in about 10% of females leading to an increased risk for cervical and other anogenital cancers.

Recombinant DNA technology led to the development of the HPV vaccine (HPV4) that includes VLPs (viral-like particles) of the oncogenic types 16 and 18 and in one vaccine, the addition of two types causing over 90% of anogenital warts—6 and 11 (107). Serotypes 16 and 18 are responsible for over 70% of cervical cancers and cross-over immunogenicity may lead to proposed protection from up to 80% of cervical cancer cases (108). The HPV vaccine contains the L1 protein that self-assembles into VLPs that are immunogenic but non-infectious by mimicking the HPV virion. Despite low HPV vaccine uptake (*vida infra*) the prevalence of the covered HPV types (i.e., 6, 11, 16, 18) dropped 56% among females aged 14 to 19 years—i.e., from 11.5% in 2003-2006 to 5.1% in 2007-2010 (109).

The HPV vaccine (containing serotypes 6, 11, 16, and 18) is given in three intramuscular injections at 0, 2, and 6 months with minimal intervals between doses 1 and 4 at 4 weeks and 12 weeks between doses 2 and 3. It is FDA-approved for females and males between 9 and 26 years of age; it is recommended to give this vaccine before the initiation of any sexual behavior. The vaccine effectiveness for one dose is 82%. Even if one is infected with one HPV, the vaccine is recommended since it is unlikely the person has been exposed to both cancer promoting types. Providing the HPV vaccine does not replace the recommendation for cervical cancer screening for females (110). Though there is no evidence of teratogenicity, it is not given to pregnant females since data on this is still limited. Contraindications to the HPV vaccine include history of allergic reaction to a previous HPV vaccine injection, Baker's yeast, or other vaccine components.

HPV vaccination has not been as well accepted by the public as the classic childhood vaccines, partly because of fear of side effects promoted by anti-vaccine forces. One manner to counter this reluctance is clear clinician endorsement that this is a safe, effective, and CDC as well as clinician-recommended immunization (111-114). Side effects are minimal and based on 21,194 VAERS reports in females from 56 million doses given between June of 2006 and March of 2013. Reported side effects include 92.1% that were listed as "non-serious": dizziness, fever, hives, local injection site reactions (i.e., pain, redness, swelling), nausea, and headache (115).

There were 7.9% of side effects listed as "serious" that included headache, nausea, vomiting, fatigue, dizziness, syncope, and generalized weakness (115). In addition to prophylactic immunization protocols, research is occurring on therapeutic strategies for HPV-associated disorders including cancers (116). Other anti-STD vaccines under research include vaccines against *Neisseria gonorrhoeae*, herpes simplex virus, *Chlamydia trachomatis*, and the HIV virus (117, 118).

HEPATITIS A IMMUNIZATION

In 2006 the CDC recommended that all children 12 to 23 months of age receive two doses of the hepatitis A vaccine. Data revealed it was widespread in the United States and was capable of causing significant morbidity with increased health care costs and loss of days from work or school. Rates of hospitalization from hepatitis A infection vary from 11 to 22%, and adults lose an average of 27 days from work. Those older than 23 months who were not vaccinated earlier can be covered through 18 years of age. The CDC Healthy People 2020 goal is 85% for those 19-35 months of age.

High-risk conditions for this virus include traveling to countries with a high Hepatitis A prevalence, those using illegal drugs, those with chronic liver disease, and men having sex with men (119). Pre-vaccination serologic testing may be useful for some adults, such as those over 40 years of age, those born or living for a prolonged time in places with high hepatitis A infection, and certain populations in the US (such as Hispanics, native Americans, or Alaskan natives). There are an estimated 1.4 million cases of hepatitis A in the world, and research notes that 90.8% of developing world children with chronic liver disease are exposed to Hepatitis A; thus, Hepatitis A vaccination is recommended to protect these children (120).

HEPATITIS B IMMUNIZATION

Annually there are approximately 140,000 cases of hepatitis B infection, with 70% noted in adolescents and young adults in the US; overall there are 1.2 million persons infected in the U.S. and the incidence is about 2.8 per 100,000 population (121). There are over 5,000 new carriers each year and 5,000 deaths each year from hepatitis B in the United States. There are approximately 350 million persons with chronic hepatitis B infection in the world.

Table 3. Risk factors for hepatitis B infection

Multiple sex partners (including more than one partner in last 6 months)
History of sexually transmitted diseases
Male-male sexual behavior
Intravenous drug use
Use of contaminated needle (body piercing, tattooing)
Requiring hemodialysis or clotting factor
Person from a country where Hepatitis B infection is common
Caring for or living with a person with Hepatitis B infection
Health care workers

Hepatitis B infection leads to hepatitis of various types: acute, chronic, and fulminant. Table 3 lists known risk factors for infection from this DNA virus, although 25% of infected persons do not have any of these risk factors. Faulty screening of donated blood and injection of illegal drugs accounts for many cases of Hepatitis B infections in the world—the latter resulting in 16 million annual cases.

Research notes that 39.1% of developing world children with chronic liver disease are exposed to hepatitis B and universal hepatitis B vaccination is recommended to protect these children (120). The CDC recommends that the hepatitis B vaccine be given a birth, 1-2 months, and 6 to 12 months of age. Hepatitis B vaccine is a recombination of antigenic groups (hepatitis B incorporated into plasmids) and has been available in the US since the mid-1980s. One of the doses should be given at or after 6 months of age to ensure lifelong immunity. There is a two-dose vaccine series that is only available for adolescents between 11 and 15 years of age.

Most adults with diabetes mellitus will become high risk conditions hepatitis B infection due to the development of chronic liver disease and end stage renal disease; thus, those with diabetes are at risk for increased morbidity and mortality from hepatitis B. All three doses of the recommended 3-dose vaccine series are required to provide maximum protection as noted by various studies including a recent study in India that recorded a seroprotection rate of 49.1% after the first dose, 86.9% after the second dose, and 96.7% after the third dose; the rate was 89% by the end of the second year and 85.5% by the end of the third year post-vaccination (122). The importance of providing a birth dose of hepatitis B vaccine has been shown by studies around the world (123). There is no proven link between hepatitis B vaccination and the development of multiple sclerosis (124).

Coverage should insure protection of newborns by beginning the hepatitis B series within 12 hours of birth. If a mother is positive for HBsAg and HBeAg, 70%-90% of her infants will become infected without post-exposure prophylaxis; the risk of perinatal transmission is 10% if the mother is positive only for HBsAg. An infant born to an HBsAg+ mother should receive the hepatitis B vaccine and also Hepatitis B Immune Globulin (HBIG) within 12 hours of birth. Up to 90% of infected infants develop a chronic infection with HBV. Pregnant women should be tested for hepatitis B (i.e., HBsAg) with each pregnancy since their Hepatitis B status can change.

VARICELLA IMMUNIZATION

Varicella (chickenpox) is the most common vaccine preventable disease in the United States and immunization begins with the 12 to 15 month old and the routine second dose is recommended for all children 4 to 6 years of age. The vaccine (*Oka-Merck strain*) is also suggested for all adolescents and adults who have not been infected with the varicella virus in a schedule of 2 doses, with a minimal interval of 3 months if under age 13 years and 4 weeks if over 13 years of age (125). Antibodies develop after the first dose in 78% and 99% after the second dose.

Infection can develop after immunization, though it is much milder with fewer than 50 lesions that are mainly maculopapular and not vesicular. It has not been shown that the risk of breakthrough infection rises the longer one is from vaccination. Risk of breakthrough infection can be lowered with a second varicella dose. A natural infection without immunization protection can lead to 300 to 500 blisters.

Table 4. Criteria for evidence of varicella immunity

1. Born in the US before 1980 (not used as criteria if pregnant or for health care personnel)
2. Documentation of appropriate vaccination
3. Laboratory documentation of immunity
4. Clinician report of herpes zoster history
5. Others

Efficacy of the vaccine is up to 90% against infection, 95% against moderate to severe disease and over 90% retain effective antibody levels for at least 6 years. Criteria for evidence of immunity to varicella are noted in Table 4 (126). Prior to the introduction of this varicella vaccine in the United States in 1995, 11,000 persons were hospitalized each year from varicella infection (2-3 per 1,000 healthy children and 8 per 1,000 adults) with one child and one adult dying each week from this infection, 80% of deaths occurred in previously "healthy" individuals (125). Unfortunately countless millions of infections occur in the world each year, secondary infection with group A Streptococcus may occur, and varicella can be teratogenic in pregnancy.

The fatality rate of varicella infection is 1 per 100,000 for those 1 to 14 years of age, 2.7 per 100,000 if 15 to 19 years of age, 8 per 100,00 for those 20 to 29 years of age, and 25.2 if 30 to 49 years of age (125). Persons over 19 years of age account for only 5% of varicella cases in the United States, but 35% of the deaths. The implementation of the varicella vaccine program in the United States resulted in a 97% decrease in deaths from this virus in persons under age 20 years and 96% decrease in those under age 50 years (127).

PNEUMOCOCCUS IMMUNIZATIONS

Streptococcus pneumoniae is a bacteria that can causes serious infection in individuals of all ages, especially in those with chronic illness (128-131) (see Table 5). All children should receive the pneumococcal conjugate vaccine (PCV13) at 2,4,6, and 12-15 months of age;

PCV-13 has replaced the PCV-7 in which only 7 serotypes are covered versus the current 13 (132). Use of the PCV vaccine at or after age 5 is dependent on the underlying chronic illness that is present. Those who are 6 to 18 years and adults 19 years and older should receive one PCV (if there is no previous PCV history) for cochlear implants, cerebrospinal fluid leakage, and immunosuppression due to HIV, asplenia (anatomic or function [i.e., sickle cell disease]), malignancy, and others (133-135). Use of PCV vaccine has lead to less invasive pneumococcal disease in children who are less than 5 years of age with 99 cases/100,000 persons in 1998-1999 dropping to 21 cases per 100,000 in 2008. There is an increased risk of febrile seizure with simultaneous use of PCV 13 and inactivated trivalent influenza vaccine (II3).

Table 5. Conditions with increased streptococcus pneumoniae risk

Age (at or over 65 years)
Alcoholism
Asplenia (anatomical or functional)
Cancer
Chronic cardiovascular disorders
Chronic pulmonary disorders
Chronic renal failure
Diabetes mellitus
HIV infection
Nephrotic syndrome
Sickle cell disease
Others

The *pneumococcal polysaccharide vaccine* (PPSV23) is recommended for persons (2 years of age and older) at high risk of S. pneumonia infections, as noted in Table 5 (132, 133). It reduces the rate of drug-resistant *Streptococcus pneumoniae* (especially type 19A) and provides coverage for 23 of the 90 pneumococcal serotypes (129). One dose is given to persons 2 to 18 years of age with cardiac or kidney disease, diabetes mellitus, chronic pulmonary disease, alcoholism, CSF leaks, or cochlear implants. Two doses are given to those 2 to 18 years of age with immunosuppression caused by HIV, asplenia, sickle cell, and malignancy; the two doses are separated by a minimum of 5 years. It is not contraindicated because of pregnancy (see the Maternal Immunization section—vida infra).

Introduction of the pneumococcal conjugate vaccine into the South African public immunization program has resulted in less pneumococcal morbidity and mortality (136). PPSV-23 is 60-70% effective in preventing invasive disease. It appears to be less effective in preventing non-bacteremic pneumococcal pneumonia and also is less effective in those with significant underlying illness.

Those at high risk for pneumococcal infection can receive the PPSV-23 vaccine including those 19 to 64 years of age who have asthma or smoke cigarettes and all those 65 years of age and older. One dose is given and a second dose can be given 5 years or more after the first dose; no more than 2 lifetime doses are recommended for those at high risk for complications from infection with *Streptococcus pneumonia* (128, 131). Efficacy of PPSV23 is about 60% to 70% in preventing invasive pneumococcal disease. Implementation of pneumococcal vaccines around the world will improve global health because of reduced health consequences of this devastating infection (137).

INFLUENZA VACCINES

Influenza is caused by an enveloped RNA orthomyxovirus with two main types (A and B) that annually leads to millions of symptomatic infections globally. Type A is subdivided using two surface proteins: **H**emagglutinin and **N**euraminidase; the most common A strains are H1N1 and H3N2. There have been four influenza pandemics in the world over the past century, including the infamous Spanish influenza pandemic of 1918-1920 (see Table 6) (138). Public health officials remain vigilant for the possibility of H and N strains that come from animals (i.e., pigs, birds, others) and may cross over to humans with hybrid strains. Currently three hybrid strains are being watched in the US: H5N1 (pathogenic avian strain from southeastern Asia), H7N9 (strain from poultry in China), and H3N2v (pig strain in the US).

Table 6. Influenza type A pandemics

Year	Subtype	Severity of Pandemic
1889	H3N2	Moderate
1918	H1N1	Severe
1957	H2N2	Severe
1968	H3N2	Moderate
2009	H1N1	Mild

In the Northern Hemisphere a seasonal pattern of influenza occurs annually starting in the fall and ending in April. There are typically four different influenza viruses circulating and produce epidemics lasting 8 to 10 weeks. Though laboratory testing is not necessary in most mild cases, lab testing is available, and depending on local medical capabilities as well as recommendations, consists of culture-based tests, antigen-based tests (direct fluorescent antibody, enzyme immunoassays), nucleic acid amplification tests (Singleplex, Multiplex), and serology.

The highest prevalence rates usually occur in children, and the highest rates of complications (i.e., hospitalizations, deaths) are usually seen in those under age 5 (especially infants), those over 65 years of age (“seniors”), and those with immunocompromised states. During each influenza season in the United States, 200,000 are hospitalized with over 35,000 deaths, mostly in the elderly and those under 5 years of age. Mortality rates are 2.7% higher when H3N2 is predominant. H1N1 tends to have a higher attack rate in those over age 25 but not over age 65 years.

Viral changes from genetic reassortment (i.e., antigenic drift or shift) alters one’s immunity to influenza each year, particularly the ability to deal with the changing hemagglutinin antigen. The vaccine-induced immunity does not last from year to year and thus, a new vaccine is introduced each year in attempts to deal with these viral changes. Unfortunately, millions of humans avoid this yearly vaccine with potentially devastating results in some. Starting with the 2011 to 2012 influenza season, allergy to eggs is a precaution and not a contraindication to the influenza vaccine. Those with a history of anaphylactic reaction to the influenza vaccine should be under the care of an allergist if further influenza immunization is given (139). Vaccination of pregnant females is recommended to protect infants under 6 months who are too immunologically young to receive the influenza vaccine (140).

Table 7. High risk groups for influenza complications

1. Diabetes mellitus and other metabolic disorders
2. Cardiovascular disorders (not hypertension)
3. Asthma and other chronic pulmonary disorders
4. Nephrotic syndrome and renal failure
5. HIV infection and other immunosuppressive disorders
6. Those with spinal cord injuries that increase
7. aspiration risks
8. Sickle cell disease; other hemoglobinopathies
9. Pregnancy
10. Children and adolescents (to 18 years of age) on long
11. term aspirin management

Table 7 lists conditions that place individuals at high risk for morbidity and mortality from influenza infection, though anyone can become very ill from this infection, with death a potential risk (141-143). Current CDC recommendations include universal influenza vaccination each year for all those over 6 months of age, since all are at potential risk from this infection. This is in addition to recommendations covering those at high risk which have been in place since the early 1960s in the United States.

Pregnant females, even without other high risk conditions, carry a 3 to 4 times increased risk for hospitalization and even death from influenza infection because of the pregnancy (see the maternal immunization section—vida infra). This high risk situation is substantially lowered with receiving the intramuscular influenza vaccination. In the United States, coverage of pregnant females with annual influenza vaccine is less than 50% (range: 33.7% to 49.2%) (144). Though fears have increased for an Avian influenza (H5N1) epidemic or pandemic in the United States and the world, there is no evidence that such an event is imminent—though certainly possible (145). Recent improvements in the preparedness for pandemic influenza have been noted in eight Central American countries between 2008 and 2012 (146).

Recent changes in influenza formulations include different amounts of antigen (i.e., high-dose vaccine with four times more antigen for those over 65 years of age), different delivery (intradermal), change to quadrivalent vaccines (covering two influenza type A strains and two B strains), and egg-free vaccines. The three-strain inactivated influenza vaccine (trivalent [IIV3]: 2 A, 1 B) is being replaced by the quadrivalent inactivated influenza vaccine (IIV4:2 A and 2 B); the live, attenuated influenza vaccine is now LAIV4. Intramuscular IIV4 is for anyone 6 months of age and older during the influenza season, which is October to May in the United States. LAIV4 is given intranasally is approved for healthy persons between 2 and 49 years of age. LAIV4 is not given to pregnant females since there is not enough data to assess its safety in pregnancy, though there is no data to indicate toxicity or teratogenicity in this situation. New vaccines may be more costly and thus, clinicians should use the influenza vaccine(s) that are available in one's country and practice.

Inactivated influenza vaccine is recommended for pregnant females in the last trimester (vida infra). Recent studies have noted the higher-induced mortality from pandemic H1N1 influenza in pregnant females and their fetuses in contrast to the healthy, non-pregnant population (147,148). Vaccination during pregnancy lowered the risk of being diagnosed with influenza, did not increase fetal deaths, and may have lowered the risk of fetal deaths from the 2009 Influenza A (H1N1) pandemic in Norway (148). As there is substantial risk to the pregnant female as well as the fetus (infant), influenza vaccination should occur at the start of the influenza season (25).

Immunity from the influenza vaccine wanes after 8 to 10 months. It is up to 80% effective in healthy individuals under 65 years of age. Among sickly elderly individuals, the influenza vaccine is less effective: 80% effective in prevention of death, up to 60% effective in prevention of hospitalization, and up to 40% overall efficacy (142).

Each influenza season results in changes in the types of strains that are predominant and population groups at most risk. For example, the influenza vaccine for the 2011 to 2012 season in the U.S. was the same for the previous year: A/California/7/2009 (H1N1)-like virus, an A/Perth/16/2009 (H3N2)-like virus, and a B/Brisbane/60/2008-like virus. Influenza A (H1N1) predominated but H3N2 (influenza A) and influenza B viruses were also seen in the 2013-2014 influenza season in the US; increased hospitalization rates were reported in those 50 to 64 years of age (149). H3N2 (influenza A) was dominant during the 2012-13 influenza season in the United States. The flu strains in the 2014-2015 vaccine are the same as found in the 2013-2014 season in the United States.

ROTAVIRUS VACCINES

Rotavirus is a viral infection that is the leading cause of severe diarrhea in those under 5 years of age leading up to 70,000 hospitalizations in infants and young children in the U.S. with 20 to 60 deaths annually (150,151). It leads to over 500,000 deaths in children under age 5 years each year in developing countries (152,153). Rotavirus infection causes a viral gastroenteritis with severe emesis, diarrhea, and dehydration. It is the most common case of diarrheal diseases in young children in the world. Prior to the current rotavirus immunization program that was begun the US in 2006, 95% of children had this infection by age 5 (150).

Introduction of rotavirus vaccines into the South African public immunization program has resulted in less rotavirus related morbidity and mortality (153). Success has also been seen in other countries, such as recently noted in Nicaragua where other main viral causes (i.e., norovirus, sapovirus) as well as Giardia lamblia are found in children with diarrhea) (154). Use of rotavirus provides up to 85-90% protection against rotavirus-induced hospitalization and is 80% protective in preventing emergency department treatment. Also, use of a live rotavirus vaccine appears to be safe when utilized to protect infants hospitalized in the NICU (155).

Two live oral rotavirus vaccines (RV5 and RV1) are currently available in the U.S. and many other countries (150, 152, 156). One is derived from an attenuated human strain (89-12) rotavirus (RV1) and the other contains five bovine-human reassortant strains (RV5) (152). Both vaccines have high efficacy rates and are not associated with increased rates of intussusceptions that were noted in 1999 with the previous vaccine. Contraindications to these vaccines are noted in Table 8, and include a history of intussusception. Prior to the vaccine availability intussusception occurred in 44 per 100,000 (1 in 2300) by one year of age, 37% required surgery, and 0.2% (4 infants) died (157). The risk of intussusception increases to 1 extra case in 20,000 to 100,000 vaccinated infants.

The vaccines are given to young infants, beginning at two months of age. RV1 Is given at 2 and 4 months of age versus RV5 which requires three doses at 2,4, and 6 months. Unfortunately most countries, including those with the highest burden of rotavirus disease, have not placed the rotavirus vaccines as part of their national vaccine programs (151). Ways to improve this situation in tropical countries include addressing the cost of these vaccines, continued education of governments as well as clinicians, and use of zinc supplementation to improve the performance of oral rotavirus vaccines in developing countries (151). Expansion of age limits for this vaccine are also proposed (158).

Table 8. Contraindications to the rotavirus vaccines

Demonstrated history of hypersensitivity to the vaccine or any of its components
History of intussusception
History of uncorrected congenital gastrointestinal tract malformation that may lead to intussusception
History of SCID (severe combine immunodeficiency)

TYPHOID FEVER VACCINES

Typhoid fever is a historical global disease due to consumption of water or food that contains feces from a person with typhoid; the etiologic bacterium is *Salmonella enterica enterica*, serovar Typhi. Infection can lead to high fever, weakness, abdominal pain, anorexia, fatigue, rash, and other symptoms. Approximately 30% of infected persons die if not treated with hydration, and antibiotics. Prevention is with sanitation, hygiene, and in endemic areas—vaccination. Two vaccines are currently available—an inactivated vaccine and a live, attenuated oral vaccine. Typhoid vaccination is effective and recommended if one is traveling to or living in an endemic typhoid fever area (159).

YELLOW FEVER VACCINE

Yellow fever is an acute viral illness due to the yellow fever virus leading to fever, anorexia, nausea, chills, headaches, back pain, and other muscular pain. It is spread via a female mosquito (i.e., Aedes aegypti) and can lead to involvement of the liver and kidneys. It appeared in Africa and spread to South America in the 17th century, eventually leading to epidemics in the Americas and Europe in addition to Africa. Widespread vaccination programs decreased yellow fever infestation from the 1940s to 1960s while reduced funding for immunization lead to an increase in this infection since 2006 (160). Currently yellow fever is found in tropical areas of Africa and South America with over 200,000 global infections and 30,000 deaths each year—mostly in Africa (161). This is yet another piece of data that serves to remind us that all countries must never let up in the constant war on vaccine preventable diseases.

The yellow fever vaccine (17DD sub-strain of yellow fever vaccine: YEL-AND) is available and recommended for those living in endemic countries as well as those traveling to endemic areas. One dose is needed to confer lifelong immunity and a booster dose is not recommended (160). Adverse effects from the vaccine are infrequent but include neurological (neurotropic, neurological autoimmune disease) that is highest in 5 to 9 years olds (2.66 per 100,000 vaccine doses), with a national analysis in Brazil finding 0.83 cases per 100,000 vaccine doses (162). These neurological adverse events usually have a favorable outcome and do not negate the need for nor the safety of the yellow fever vaccine (163).

JAPANESE ENCEPHALITIS VACCINE

Japanese B encephalitis is due to the Japanese encephalitis virus spread by mosquitoes (*Culex tritaeniorhynchus, Culex vishnui*) and found especially in east Asia and southeast Asia (164). Most infections are without symptoms but one in 250 infections can cause acute encephalitis which can lead to death, deafness, hemiparesis and other adverse effects. Three vaccines are available on the global market: SA14-14-2, ChimeriVax-JE, and IC51. The US CDC recommends vaccine protection for children (2 months through 16 years) at risk for this potentially serious infection (164, 165).

IMMUNIZATIONS FOR PREGNANT FEMALES

Pregnant females should be fully protected from vaccine preventable disorders (VPDs) both for the health of the mother and her offspring (166). Immunologic protection in the pregnant mother can confer protection for her newborn to various diseases, including influenza, tetanus, pertussis, diphtheria, hepatitis B virus, respiratory syncytial virus, Group B streptococcus, and *Haemophilus influenzae* type b (40, 123, 125). Very low risk is conferred to the pregnant female or offspring by use of killed vaccines. According to the CDC: “Benefits of vaccinating pregnant women usually outweigh potential risks when the likelihood of disease exposure is high, when infection would pose a risk to the mother or fetus, and when the vaccine is unlikely to cause harm (167).”

Studies of pregnant women given influenza and poliomyelitis vaccines in the 1950s and 1960s noted that these vaccines were not harmful to the mother nor the fetus/infant; studies looking at the offspring up to 7 years of age noted no increase in teratogenicity, learning disorders, nor malignancy (168, 169). Influenza vaccination to pregnant females decreases influenza morbidity and mortality in both the mother and the infant (147, 148). One study in Bangladesh giving inactivated influenza vaccine (TIV) to pregnant females reported a 63% vaccine efficacy and a lowering of influenza-like illness in infants by 29% and mothers by 36% (170). Studies in other countries have consistently revealed the safety and efficacy of influenza vaccine (TIV) with reduction in maternal as well as fetal/infant morbidity and mortality (169).

Though there is no evidence of teratogenicity using U.S. FDA approved, attenuated, live viral vaccines (i.e., MMR, Varivax, LAIV), they should be avoided on a theoretical basis, one month prior to and during pregnancy. Women should be advised to avoid conception for one month after receiving live vaccines. Neither killed nor live vaccines are contraindicated for breast-feeding females. Breastfeeding is not a contraindication for any vaccine except for smallpox vaccine.

Maternal immunization is used to improve passive immunity of infants to microbes that can severely harm them, and has been recommended by leading national health care organizations in the US since 1957. The key is to protect both mother and infant. Most maternal IgG antibody crosses the placenta in the third trimester, but the best timing seems to be when the vaccine is given at least 6 weeks prior to delivery; vaccination of the mother has not been shown to be detrimental to primary infant immunization (171).

The CDC ACIP currently recommends two vaccines for pregnant females: inactivated influenza and Tdap (tetanus toxoid, reduced diphtheria toxoid, and acellular pertussis) (169, 171). Females given influenza (TIV) or tetanus toxoid (TT) noted increased IgG antibodies to maternal vaccine antigens in cord and infant serum (172). Since antibody levels drop in subsequent pregnancies, pregnant women should receive 1 dose of Tdap during every pregnancy with the best timing between 27 and 36 weeks of gestation to best provide maternal antibody placental transfer to the fetus. Vaccination during the third trimester confers the highest antibody concentrations to the fetus/newborn. It takes about 2 weeks after maternal vaccination to reach maximal immune response in the infant. Active transport of maternal immunoglobulin G does not significantly occur before 30 weeks of gestation (173).

Death from pertussis occurs primarily in infants under 2 months of age. Infant cord blood reveals increased pertussis antibody if their mothers received Tdap during pregnancy, and in 2012, the CDC recommended that all pregnant women receive Tdap during the third trimester regardless of previous Tdap history (174). Tdap given before the third trimester does not result in transfer of sufficient pertussis antibody for the fetus (175). A 2012 study in England has noted the safety and efficacy of Tdap given in the third trimester with reduction of infant deaths due to pertussis (176).

A randomized, double-blind, placebo-controlled crossover study of the effects of Tdap given during pregnancy from 2008 to 2012 noted that the vaccine was safe for mother as well as infant, that it was immunogenic for the mother, and that there was effective transplacental antibody transfer (177). Interference with infant vaccination was not seen, though more research is needed to see if interference with other infant vaccinations does occur (178). The effect of repeated Tdap dosing during subsequent pregnancies is not clear, for example, could it induce reduced antibody production; more research is needed to monitor the effects of this recommendation (178).

A number of issues influence the transport of maternal IgG during pregnancy (Table 9). For example, maternal IgG transfer mainly occurs after 32 weeks of gestation and thus, a premature infant has low levels in contrast to a full term infant who may have higher levels than the mother at delivery. There are subtypes of maternal IgG such as IgG1 and IgG2; the former is stimulated by tetanus toxoid which induces protein antigens in contrast to pneumococcus vaccine which induces polysaccharide antigens that stimulates IgG2 (166). High levels of maternal IgG can decrease antigen-specific IgG transfer because of competitive binding to Fc receptors (placental) (169). If the mother is infected with HIV or malaria, this can lower maternal IgG placental transfer because of defective Fc receptor ability (179).

Table 9. Issues affecting transport of maternal IgG during pregnancy (170A)

Maternal placental integrity
Vaccination timing
Total concentration of maternal IgG
IgG subtype

Research has shown that other vaccines can be given safely to pregnant females to provide antibodies with immunogenic effects to the infant in a safe manner. These include Haemophilus influenzae serotype b, group B streptococcus, meningococcus, and pneumococcal vaccines (169). Research is currently looking at the use of cytomegalovirus, herpes simplex virus, and respiratory syncytial virus vaccines (169).

Varicella and MMR vaccines should be given to susceptible females immediately postpartum. Subclinical fetal infection has been identified via serology in 1-2% of infants born to susceptible mothers (regardless of the vaccine strain); congenital rubella syndrome has not been found in the babies of 321 susceptible women given rubella vaccine who completed their pregnancies (180).

Hepatitis B

One classic study of pregnant females given hepatitis B immunoglobulin and hepatitis B vaccine noted that passive active immunization can be started safely during pregnancy and that response to the vaccine was “weak”; monitoring of anti-HepB one month after the initial vaccine series was recommended (181).

Group B Streptococcus

Another study looked at giving pregnant women a polysaccharide vaccine to group B streptococcus and provided some passive immunity against systemic Type III group B Streptococcus infection in most newborns, though more research was recommended (182). A follow-up report by the same lead author noted immunizing pregnant females with group B streptococcal type III capsular polysaccharide-tetanus toxoid conjugate vaccine was a safe and immunogenic. The vaccine resulted in effective transfer of transplacental antibody to the newborn with good levels until 2 months of age (183). Research is focusing on provision of a global maternal immunization program for group B Streptococcus, which is the most common invasive infection in infants less than 3 months of age in the United States (184, 185).

Haemophilus influenza type b

A study in The Gambia noted that maternal immunization with Haemophilus influenzae type b polysaccharide-tetanus protein conjugate vaccine may lower the rates of Hib disease in infants who are too young to receive their own immunization (186). Other research on use of this vaccine for maternal immunization in developing countries has shown it to be safe and immunogenic with protective serum and cord antibody levels (187). The Haemophilus influenza conjugate vaccine is better than the polysaccharide vaccine in raising infant antibody levels at birth and at 2 months of age; also, immunization of the mother with conjugate vaccine does not reduce the infant's reaction to conjugate vaccine in comparison to infants with mothers who did not receive Haemophilus influenza vaccination (188).

Streptococcus pneumonia

Research on the pneumococcal polysaccharide vaccine (PPV23) has shown it to be a safe vaccine for pregnant females and there is good placental antibody transfer (189-191). The actual effect of maternal immunization with PPV23 on protecting infants is unclear at this time. It is known that polysaccharide vaccines do not stimulate a vigorous T-cell with memory B-cell effect and limited studies to date have not demonstrated lowering of neonatal infection nor nasopharyngeal colonization in infants at 2-3 months of age following maternal PPV23 immunization (191).

Neisseria meningitides

Limited studies have been conducted on meningococcal vaccines and pregnant females. Use of the polysaccharide vaccine in pregnancy does result in antibody rise in both mother (sera and breast milk) and infant though transplacental antibody levels were not consistent (192). Use of meningococcal vaccine in pregnant women has not been shown to be harmful upon reviewing the U.S. Vaccine Adverse Event Reporting System (193).

Poliovirus vaccine

Though inactivated poliovirus vaccine is not recommended for pregnant females, extensive use of polio vaccine during the 1950s with pregnant females noted it was safe and effective for both mother and infant (194, 195).

Herpes simplex virus (HSV) vaccine

Neonatal herpes is a major infection with a high mortality rate. While no vaccine has been shown to be effective in protecting the newborn from maternal infection, research is currently looking at a number of potential vaccines for the future (196, 197).

Cytomegalovirus vaccine

Cytomegalovirus (CMV) is another serious infection in newborns with many complications, and the pregnant female may acquire CMV infection and transmit it to her newborn. One study of postpartum women susceptible to CMV who were given a CMV vaccine noted a 50% efficacy (198).

Respiratory syncytial virus (RSV) vaccine

RSV is a major cause of respiratory disease (i.e., bronchiolitis and pneumonia) in infants, especially those under 6 months of age; there is minimal treatment and an expensive monoclonal antibody, palivizumab that can be used prophylactically for infants judged to be at high risk for this infection during RSV season. Research on an RSV vaccine (formalin-inactivated) for infants in the 1960s was not effective and in fact led to increase infection (199). Since infants under 6 months are not good vaccine candidates, maternal vaccination would seem to be a better option to protect the infant. Research in this area is underway with a number of potential vaccines being studied (199, 200).

CONCLUSION

Immunizations for all citizens of the world should be an important goal of all clinicians, including those dealing with children and adolescents in developing and developed countries. Vaccine preventable diseases (VPDs) continue to take a devastating toll on these vulnerable human beings. Failure to provide available vaccines is a common problem in the world for various reasons; poverty, limited health care systems, ignorance on the part of individuals or governments, difficulty in keeping up with ever more complex and changing immunization schedules, failure to fund agencies responsible for immunization policies in specific regions, failure to understand barriers to vaccinations unique to an area, and the growing influence of anti-vaccine movements fueled by false information from the media as well as the internet (126, 201). All countries should carefully review their immunization programs and improve them as needed for the health of their citizens who will benefit greatly from vaccines to control and eliminate VPDs (7, 146, 154, 202, 203).

Despite these issues, vaccinology has been one of the greatest advances in modern medicine in the 21st century that can potentially benefit billions of human beings on earth (204-210). Smallpox has been eliminated from the globe and poliomyelitis has been wiped out in many parts of the world; in addition, diseases such as tetanus and diphtheria have been controlled in some parts of the world (22). Children are now safer from a variety of viral and bacterial infections that were previously devastating. Research is seeking to apply vaccine science in dealing with HIV, tuberculosis, malaria, and various forms of cancer (211).

A key strategy to improve the world’s health is lifelong vaccination of VPDs starting in early childhood and continuing throughout life. Those traveling internationally need to receive the recommended vaccines from their own country and as well as those recommended for their destination(s). This is important not only to protect the traveler and but also to protect foreigners who come in contact with the traveler (97, 212). Another strategy is to ensure the immunization of healthcare providers to protect the safety of patients (213). Vaccination of children at high risk for VPDs is also important (21).

The actual impact of vaccines on morbidity and mortality in various countries may take years to verify, but the role of the clinician in this important process remains critical to ensure maximum success in the global campaign to achieve protection against VPDs in over 90% of the world’s population. Sometimes the impact is rapid, as noted with decreased deaths from measles, pertussis, and diphtheria; while for other diseases like hepatitis B and HPV, the impact can take years to determine. Effects of vaccines on invasive pneumococcal disease and rotavirus gastroenteritis in developed countries is easily documented by the decrease in disease incidence and hospitalizations (214).

Maternal vaccination (inactivated influenza and Tdap) is recommended for pregnant females to help strengthen maternal and neonatal health since both populations are vulnerable due to a reduced immunological state (171). Indeed, vaccines save lives around the world and clinicians must remain pro-active in educating their patients and their parents in order to aggressively counter-act the pseudo-science of the anti-vaccine proponents (214). Clinicians must be prepared to deal with a public who obtain inaccurate health information from the internet, medical/dental smartphone Apps, anti-vaccine groups, and others (17, 215, 216).

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SECTION THREE: ACKNOWLEDGMENTS

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Chapter 21

ABOUT THE EDITOR

Joav Merrick, MD, MMedSci, DMSc, born and educated in Denmark is professor of pediatrics, child health and human development, Division of Pediatrics, Hadassah Hebrew University Medical Center, Mt Scopus Campus, Jerusalem, Israel and Kentucky Children's Hospital, University of Kentucky, Lexington, Kentucky United States, professor of public health at the Center for Healthy Development, School of Public Health, Georgia State University, Atlanta, United States, the medical director of the Health Services, Division for Intellectual and Developmental Disabilities, Ministry of Social Affairs and Social Services, Jerusalem, the founder and director of the National Institute of Child Health and Human Development in Israel. Numerous publications in the field of pediatrics, child health and human development, rehabilitation, intellectual disability, disability, health, welfare, abuse, advocacy, quality of life and prevention. Received the Peter Sabroe Child Award for outstanding work on behalf of Danish Children in 1985 and the International LEGO-Prize ("The Children's Nobel Prize") for an extraordinary contribution towards improvement in child welfare and well-being in 1987. E-mail: jmerrick@zahav.net.il.

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Chapter 22

ABOUT THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT IN ISRAEL

The National Institute of Child Health and Human Development (NICHD) in Israel was established in 1998 as a virtual institute under the auspices of the Medical Director, Ministry of Social Affairs and Social Services in order to function as the research arm for the Office of the Medical Director. In 1998 the National Council for Child Health and Pediatrics, Ministry of Health and in 1999 the Director General and Deputy Director General of the Ministry of Health endorsed the establishment of the NICHD.

MISSION

The mission of a National Institute for Child Health and Human Development in Israel is to provide an academic focal point for the scholarly interdisciplinary study of child life, health, public health, welfare, disability, rehabilitation, intellectual disability and related aspects of human development. This mission includes research, teaching, clinical work, information and public service activities in the field of child health and human development.

SERVICE AND ACADEMIC ACTIVITIES

Over the years many activities became focused in the south of Israel due to collaboration with various professionals at the Faculty of Health Sciences (FOHS) at the Ben Gurion University of the Negev (BGU). Since 2000 an affiliation with the Zusman Child Development Center at the Pediatric Division of Soroka University Medical Center has resulted in collaboration around the establishment of the Down Syndrome Clinic at that center. In 2002 a full course on “Disability” was established at the Recanati School for Allied Professions in the Community, FOHS, BGU and in 2005 collaboration was started with the Primary Care Unit of the faculty and disability became part of the master of public health course on “Children and society.” In the academic year 2005-2006 a one semester course on “Aging with disability” was started as part of the master of science program in gerontology in our collaboration with the Center for Multidisciplinary Research in Aging. In 2010 collaborations with the Division of Pediatrics, Hadassah Hebrew University Medical Center, Jerusalem, Israel around the National Down Syndrome Center and teaching students and residents about intellectual and developmental disabilities as part of their training at this campus.

RESEARCH ACTIVITIES

The affiliated staff have over the years published work from projects and research activities in this national and international collaboration. In the year 2000 the International Journal of Adolescent Medicine and Health and in 2005 the International Journal on Disability and Human Development of De Gruyter Publishing House (Berlin and New York) were affiliated with the National Institute of Child Health and Human Development. From 2008 also the International Journal of Child Health and Human Development (Nova Science, New York), the International Journal of Child and Adolescent Health (Nova Science) and the Journal of Pain Management (Nova Science) affiliated and from 2009 the International Public Health Journal (Nova Science) and Journal of Alternative Medicine Research (Nova Science). All peer-reviewed international journals.

NATIONAL COLLABORATIONS

Nationally the NICHD works in collaboration with the Faculty of Health Sciences, Ben Gurion University of the Negev; Department of Physical Therapy, Sackler School of Medicine, Tel Aviv University; Autism Center, Assaf HaRofeh Medical Center; National Rett and PKU Centers at Chaim Sheba Medical Center, Tel HaShomer; Department of Physiotherapy, Haifa University; Department of Education, Bar Ilan University, Ramat Gan, Faculty of Social Sciences and Health Sciences; College of Judea and Samaria in Ariel and in 2011 affiliation with Center for Pediatric Chronic Diseases and National Center for Down Syndrome, Department of Pediatrics, Hadassah Hebrew University Medical Center, Mount Scopus Campus, Jerusalem.

INTERNATIONAL COLLABORATIONS

Internationally with the Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago; Strong Center for Developmental Disabilities, Golisano Children's Hospital at Strong, University of Rochester School of Medicine and Dentistry, New York; Centre on Intellectual Disabilities, University of Albany, New York; Centre for Chronic Disease Prevention and Control, Health Canada, Ottawa; Chandler Medical Center and Children’s Hospital, Kentucky Children’s Hospital, Section of Adolescent Medicine, University of Kentucky, Lexington; Chronic Disease Prevention and Control Research Center, Baylor College of Medicine, Houston, Texas; Division of Neuroscience, Department of Psychiatry, Columbia University, New York; Institute for the Study of Disadvantage and Disability, Atlanta; Center for Autism and Related Disorders, Department Psychiatry, Children’s Hospital Boston, Boston; Department of Pediatric and

Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, Michigan, United States; Department of Paediatrics, Child Health and Adolescent Medicine, Children's Hospital at Westmead, Westmead, Australia; International Centre for the Study of Occupational and Mental Health, Düsseldorf, Germany; Centre for Advanced Studies in Nursing, Department of General Practice and Primary Care, University of Aberdeen, Aberdeen, United Kingdom; Quality of Life Research Center, Copenhagen, Denmark; Nordic School of Public Health, Gottenburg, Sweden, Scandinavian Institute of Quality of Working Life, Oslo, Norway; The Department of Applied Social Sciences (APSS) of The Hong Kong Polytechnic University Hong Kong.

TARGETS

Our focus is on research, international collaborations, clinical work, teaching and policy in health, disability and human development and to establish the NICHD as a permanent institute in Israel in order to conduct model research and together with the four university schools of public health/medicine in Israel establish a national master and doctoral program in disability and human development at the institute to secure the next generation of professionals working in this often non-prestigious/low-status field of work.

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Chapter 23

ABOUT THE BOOK SERIES "PEDIATRICS, CHILD AND ADOLESCENT HEALTH"

Pediatrics, child and adolescent health is a book series with publications from a multidisciplinary group of researchers, practitioners and clinicians for an international professional forum interested in the broad spectrum of pediatric medicine, child health, adolescent health and human development.

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SECTION FOUR: INDEX

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