

The Burden of Neural Tube Defects in the United States

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Abstract

Neural tube defects (NTDs) are birth defects that occur in the brain and spinal cord resulting from failure of neural tubes to close. Causes of NTDs range from lack of folic acid supplementation to environmental factors to genetic causes. Despite the cause of birth defects of not being completely known, continuous research presents a great tool in learning more about the disease. Two main NTDs that are predominantly emphasized in the literature are spina bifida and anencephaly. Each year approximately 300,000 to 400,000 babies are born with spina bifida and anencephaly worldwide. Additionally, approximately 2500 babies are born with NTDs in the United States, which is about half the number of NTDs in European countries. Children affected by spina bifida find themselves challenged mentally, intellectually and socially. Studies reveal that spina bifida is the most common birth defect in the U.S. and that hospitalizations related to the disease costed nearly \$86 million in 2003. One of the most promising discoveries in terms of NTDs has been the link that was made between insufficient folate and increased risk of developing a NTD. The implementation of folic acid supplement in childbearing women's diet and women wishing to become pregnant decreased the incidence of NTDs in the United States. Education and statewide surveillance systems are also effective in reducing the burden of NTDs in our nation. However, addressing the issue of health disparities and improving quality of life in affected populations are suggestions that would contribute to the decline of NTDs in the U.S. Finally, continuous research is important to better understand NTDs.

Introduction

Nearly eight million babies worldwide are born every year with birth defects and 3.2 million of them are disabled for life (Mohamed & Aly, 2012). In the United States, birth defects are the primary cause of death in children who are one year of age or less, representing about 20% of newborn deaths (Mohamed & Aly, 2012). Causes for birth defects range from genetic, biologic, nutritional, or environmental factors (Mohamed & Aly, 2012). Twenty percent of birth defects are attributed to genetic causes, 10 % to nutritional and environmental factors, and about 70% remain to unknown causes (Mohamed & Aly, 2012). Neural tube defects (NTDs) are one of several birth defects that are impacted by all three causal factors. NTDs are birth defects that occur in the brain or spinal cord resulting from failure of neural tube defects to close (Osterhues et al., 2013). NTDs rate vary between 1-10 per 1000 live births depending on the geographical region and ethnicity of the mother (Imbard et al., 2013).

Each year approximately 300,000 to 400,000 babies are born with spina bifida and anencephaly worldwide (Yi et al., 2011). Additionally, approximately 2500 babies are born with NTDs in the United States, which is about half the number of NTDs in European countries (Yi et al., 2011).

Statistics of geographical regions with higher risks of NTDs can be challenging to acquire. The inability to obtain national data sample for births and deaths associated with birth NTDs and those due to lack of information on stillborn babies who lacked birth records present some of the main reasons (Mohamed & Ali, 2012). Despite such challenges, some studies still managed to designate regions that present the highest rates of NTDs based on The U.S. Census. Through information based on data management and analysis of newborn babies in different states, there are subdivisions in four U.S. regions among which differences can be examined that

include Northeast, South, Midwest and West (Mohamed & Aly, 2012). Such studies investigated the data provided by the Healthcare Cost and Utilization Project (HCUP) concerning new births affected by NTDs between 1997-2004. Results revealed that male infants were more likely to suffer from NTDs compared to female babies in the Northeast (Mohamed & Ali, 2012). Similarly, Hispanics in the South had higher risks of NTDs, while Asians in the West regions of the country had lower risks (Mohamed & Ali, 2012). Overall, the Northeast region of the country had less prevalence for NTDs and the Midwest had the highest prevalence for NTDs compared to all regions (Mohamed & Ali, 2012). It will later be discussed that knowing at risk regions for NTDs is important for implementing health policies in order to reduce the prevalence of the disease in such regions.

It is also equally important to identify the different types of NTDs so that effective monitoring, implementation and evaluation campaigns can contribute to reducing NTDs. There are several types of NTDs which include craniorachischisis, anencephaly and spina bifida (Osterhues et al.,2013). Similarly, NTDs can be categorized as open, meaning the neural tubes are exposed, or closed, meaning the neural tubes are covered by tissues (Imbard et al.,2013). Two main NTDs that are predominantly emphasized are spina bifida and anencephaly; this paper will focus on both spina bifida and anencephaly in live infants born in the United States (Yi et al., 2011). Spina bifida refers to the neural defects at the spinal column area, whereas anencephaly refers to the neural defects at the cranial level (Imbard et al., 2013). Research further emphasizes that both spina bifida and anencephaly differ in the resulting outcomes: defects in the spinal area are more likely to be treatable, although not curable; defects in the brain area are much more fatal and in most cases, only result in a few hours of life expectancy (Imbard et al., 2013).

Different types of neural tube defects

Spina bifida

Children born with spina bifida usually go through surgery within few hours of being born in order to close the gap (Yi et al., 2011). Though such children have a higher life expectancy, rising from nearly 85-90% into adulthood, and though the condition is treatable, many children unfortunately grow up with adverse outcomes such as hydrocephalus, urinary tract infection, locomotion difficulties and intellectual challenges (Yi et al., 2011).

There are four different types of spina bifida that develop depending on the severity of the disease and they include: spina bifida occulta, closed spina bifida, meningocele, and Myelomeningocele.

Spina bifida occulta, also called hidden spina bifida, develops with a very small opening on the back of the baby. It is the mildest form of the disease which usually does not affect the health of the baby (March of Dimes, 2014).

Closed neural tube defect is the form of the disease in which the bones, fat and meninges surrounding the spinal cord do not develop properly (March of Dimes, 2014). Depending on the severity of the condition, the baby may have issues associated with incontinence (March of Dimes, 2014).

Meningocele is the rarest form of the disease in which the meninges, which are the tissues that cover the spinal cord and brain, push their way out in an opening on the back of the baby. This condition does not cause any nerve damage, though it may cause issues related with incontinence (March of Dimes, 2014).

Myelomeningocele, also called open spina bifida, is the most common and most severe form of spina bifida. Part of the spina cord and meninges push through the opening on the baby's back, which may consequently cause permanent nerve damage (March of Dimes, 2014).

Additionally, depending on the severity, may cause paralysis of the lower part of the body, disabilities associated with motion, incontinence issues, hydrocephalus, and learning disabilities (March of Dimes, 2014).

Anencephaly

Unlike spina bifida, anencephaly is a fatal health condition in which the upper end of the tubes fail to close, which consequently prevent the brain from developing properly (Yi et al., 2011). Children affected with anencephaly usually die within hours or days (Au et al., 2010; Yi et al., 2011). Studies reveal pregnancies affected by anencephaly often result in miscarriages and that 50% of affected children only have a life expectancy of minutes to hours, and only 25% can get to up to 10 days (Yi et al., 2011).

Etiology

Though the exact causes of NTDs remain unclear, studies reveal that both genetic and non-genetic factors are correlated with risks for NTDs (Au et al., 2010).

Genetic risk factor

Innovative discoveries made the correlation between gene mutation and NTDs. In effect, the Methylenetetrahydrofolate reductase (MTHFR) gene mutation is a risk factor to NTDs (Levin & Varga, 2016). MTHFR is an enzyme that is important for folate metabolism in which folic acid is converted in an active form that is usable by the body; however, genetic mutation can impede this process from taking place (Levin & Varga; 2016). Researchers explain that folic acid acts through folate one-carbon metabolism, which involves amino acid and nucleotide

metabolism (Leung et al., 2013). This process results in folate methylation and nucleotide biosynthesis in the body: a process that is important for the development of the fetus (Leung et al., 2013). When this metabolic process is unsuccessful, in which nucleotides are not fully supplied with folate, it may affect the efficacy of folic acid in the body; making it a risk for NTDs (Leung et al., 2013).

Non- genetic risk factors: Lifestyle and socio-demographic factors

Lifestyle factors. Lifestyle factors contributing to NTDs include maternal pre-pregnancy diabetes and obesity (Lupo et al., 2012; Rasmussen et al., 2008). Infants born to obese mothers and those born to type II diabetic mothers may present similar pathogenic characteristics that include alteration of glucose homeostasis and hyperglycemia (Lupo et al., 2012). The research explains such drawbacks due to the fact that the embryo's pancreas development happens after the seventh week of gestation, whereas neural tubes close around the fourth week of gestation (Lupo et al., 2012). Consequently, mothers with poorly regulated glucose levels present dangers for their fetuses at the early stage of pregnancy as tube closure may be affected by increased levels of glucose (Lupo et al., 2012).

Additionally, a hospital case control study performed on mothers evaluated maternal body mass index as a risk factor for NTDs. The study revealed that maternal BMI could be a causal link between folic acid supplementation and risk for NTDs (Wang et al., 2013). The study consisted of 459 mothers with NTDs- affected births and 459 NTDs non- affected births, and analyzed the relationship between folic acid supplementation and risk for NTDs for underweight and normal weight mothers with body mass index (BMI) less than 24, and overweight mothers with BMI more or equal to 24 (Wang et al., 2013). The 459 cases of NTDs included 194 cases of anencephaly, 200 cases of spina bifida and 65 cases of encephalocele

(Wang et al., 2013). Results from the study reveal that a causal link between folic acid supplementation and increased risk for NTDs was greater in mothers with a BMI higher or equal to 24 compared to mothers who had a BMI less than 24 (Wang et al., 2013).

Socio- demographic factors. Socio- demographic factors contributing to NTDs include socio-economic status, parent education level, maternal and paternal ages and occupations, maternal use of medications during early stages of pregnancy, and maternal reproductive history including maternal country of birth and country of conception (Au et al., 2010).

Indeed, a study performed in California investigated the relationship between women with low socio-economic status (SES) risk of NTDs during the food fortification period (Au et al., 2010). At the end of the study, results showed that women who did not graduate with a high school diploma and lived in low socio-economic status presented increased risks for NTD pregnancies than women with high school diploma or higher education (Au et al., 2010). Additionally, a meta-analysis performed on pregnant women revealed that mothers over 40 years old or under 19 years old are at a greater risk of NTD pregnancies, with spina bifida being the most prevalent (Au et al., 2010). Another causal factor for NTDs is related to parental occupation: a 2002 study revealed that both fathers and mothers who worked as cooks, farm workers, janitors and cleaners using chemicals, were associated with higher risks of NTD pregnancies (Au et al., 2010). Studies also found that the use of folic acid antagonist medications such as antibacterial drugs and some serotonin inhibitors are associated with higher risk of anencephaly (Au et al., 2010). Finally, research reveals that the place of birth also affects NTD pregnancy outcomes. There are increased rates of NTDs in some sub-groups worldwide, such as Sub-Saharan Africa, First Nation Tribes in Canada and indigenous women in Australia due to lack of folic acid food fortification (Au et al., 2010).

Public Health Impact

Economic aspect. Hospitalizations related to NTDs costed nearly \$600 million in 2013 in the U.S. (CDC, 2016). Average Medicaid payments for children with spina bifida were nearly 12 times higher than the average payment for all children in Washington State Medicaid program in 1993 (Yi et al., 2011).

Social aspect. The Centers for Disease Control and Prevention (2016) statistics reveal that Hispanics have approximately 3.80 spina bifida cases per 10,000 births, while non-Hispanic black and white individuals have 2.73 per 10,000 births and 3.09 per 10,000 births respectively. To further explain the CDC data, Dr. Mills, a senior investigator on birth defects at the National Institute of Health states that “There are several explanations as to why Hispanic mothers have the highest rate of NTDs: a non- biological explanation is that more Hispanic births are identified with neural tube defects because Hispanic mothers are more likely to continue with the pregnancy due to religious reasons even when they are made aware of the fetus having a neural tube defects during an ultrasound exam. White and Black non-Hispanic mothers are more likely to terminate the pregnancy. Furthermore, Hispanics have high levels of the MTHFR genetic variance as a high factor” (Personal communication, Sept. 08, 2017).

These statistics are important to study the effects of neural tube defects in individuals progressing from childhood to adulthood not only among Hispanic sub-groups, but all involved. Such statistics are crucial in studying behavioral and psychological complications in individuals with NTDs at different stages of their lives (Essner & Holmbeck, 2010). Although school age children with NTDs encounter social challenges with their peers, studies report that adolescents are the most affected on social levels as they are transitioning from childhood to adulthood (Essner & Holmbeck, 2010).

Interpersonal factors and consequences

Adolescents who live with spina bifida may need life adjustments such as wheelchairs for mobility and catheterization for incontinence, both of which may cause a strain on social interactions with peers (Essner & Holmbeck, 2010). Consequently, the affected child may develop depression, which may lead to psychological problems in adult life (Essner & Holmbeck, 2010).

Additionally, the demands associated with having a child with spina bifida may be stressful on family members (Essner & Holmbeck, 2010). Consequently, the affected child may develop depression due to feelings of guilt (Essner & Holmbeck, 2010).

Institutional factors and consequences

Adolescents with spina bifida may have difficulties achieving normal academic standards due to neuropsychological deficits (Essner & Holmbeck, 2010). Such adolescents may develop low self-esteem due to their limitations in fully contributing their knowledge to their peers (Essner & Holmbeck, 2010).

Community- related factors and consequences

Adolescents living with spina bifida may not find enough resources in the community which would otherwise help them reach their full intellectual potential (Essner & Holmbeck, 2010). The Centers for Disease Control and Prevention (2016) states that individuals with spina bifida are affected in different times during their developmental growth. School-aged children with spina bifida may have academic challenges when in the classroom with their peers, while adolescents and adults living with spina bifida learn to adjust to life and live independently. However, adolescents and adults with spina bifida face challenges in communities such as

working and keeping a job, volunteering, finding and using transportation, living outside their parents' house and nurturing good social relationships (CDC, 2016).

Societal factors and consequences

Children who suffer with spina bifida have a higher risk of experiencing social discrimination from their peers and enduring social difficulties (Devine et al., 2012). Indeed, from school-aged children to adolescents to adults, NTDs and more specifically spina bifida not only impact the lives of those with the chronic disease, but also those of their families and communities.

Review of literature

In the review of the current literature about neural tube defects, the following main themes arise: folic acid supplementation, education, State- wide surveillance systems, prenatal surgery and the study of resistant folic acid methylation in mice.

Folic acid implementation

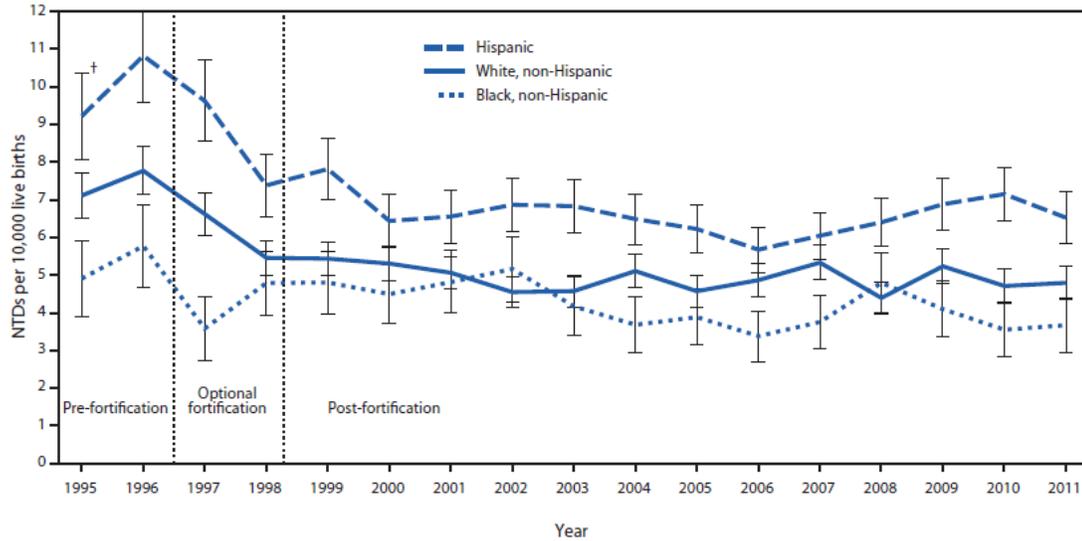
One of the most promising discoveries in terms of NTDs is the link that was made between insufficient folate and increased risks. When the causal link was made, the implementation of folic acid supplementation was developed in childbearing women's diet and women wishing to become pregnant (Kannan et al., 2007). In 1998, the Food and Drug Administration (FDA) approved folate supplementation products, then fortified grain products were produced with 100-140 micrograms of folic acid (Kannan et al., 2007). The same year, the Institute of Medicine (IOM) and the Public Health Service (PHS) recommended that women of childbearing age and women who wished to become pregnant should consume a daily dose of 400 micrograms of folic acid in order to prevent NTDs (Kannan et al., 2007). Intake of

multivitamins containing the recommended 400 micrograms of folic acid was the most utilized method to reduce NTDs (Grosse et al., 2016; Mills 2017). The implementation of recommending folic acid fortification for childbearing women who intend to become pregnant has successfully reduced the prevalence of NTDs in the United States (Heseker, 2011; Leung et al., 2013).

A randomized study performed in 45 U.S. states and Washington DC, in reproductive-aged women before and during pregnancy reported that NTD rates plummeted from 37.8/100,000 live births pre-fortification, to 30.5/100,000 live births after the mandatory Food and Drug Administration policy implementation on folic acid fortification (Honein et al., 2001). The components of the study relied on the analysis of birth certificate reports for live births in such areas between 1990 and 1999 to evaluate the impact of folic acid food fortification on NTD-affected birth prevalence (Honein et al., 2001). Overall, findings indicated a 19% decline in the incidence of NTDs following folic acid fortification in the U.S., revealing a successful initiative campaign (Honein et al., 2001; Mosley et al., 2009).

The graph below from the Centers for Disease Control and Prevention is a depiction of the success of the folic acid fortification initiative as it portrays the decline of NTDs in the U.S. from 1995 to 2011.

FIGURE. Prevalence of neural tube defects (NTDs) (anencephaly and spina bifida) before and after mandatory folic acid fortification, by maternal race/ethnicity – 19 population-based birth defects surveillance programs,* United States, 1995–2011



* Contributing programs are based in Arkansas, Arizona, California, Colorado, Georgia, Illinois, Iowa, Kentucky, Maryland, New Jersey, New York, North Carolina, Oklahoma, Puerto Rico, South Carolina, Texas, Utah, West Virginia, and Wisconsin.

† 95% confidence interval.

Alternate Text: The figure above is a combination line and bar chart showing the prevalence of neural tube defects (NTDs) before and after mandatory folic acid fortification, by maternal race/ethnicity, according to 19 population-based birth defects surveillance programs in the United States during 1995-2011. A decline in NTDs was observed for all three of the racial/ethnic groups examined between the pre-fortification and post-fortification periods.

(*Folic Acid for the Prevention of Neural Tube Defects*; 2009).

Education and awareness

Another approach that has been used to reduce the prevalence of NTDs in the U.S. is the education of women in communities about the benefits of food fortification on reducing NTDs. Studies reveal that high-risk regions of the U.S. with educational programs on the benefits of folic acid supplementation have been successful in reducing the prevalence of NTDs (Kannan et al., 2007; Prue et al., 2010).

Because Latina women have the highest rate of giving birth to children with NTDs, a survey was conducted in South Michigan in order to assess awareness of the importance of folic acid supplementation and educate Latina mothers specifically about the benefits of folate supplement (Kannan et al., 2007). A previously conducted survey on the Latina population in a

different state reported that only 17% of 471 Latina residents had heard of NTDs; 11% were aware that folic acid supplements prevented NTDs, and 80% were unaware of folate food sources (Kannan et al., 2007). This information served as a guide for the survey in South Michigan as they aimed for customer awareness. Twenty bilingual healthcare workers conducted health education sessions about folate acid supplementation in supermarkets and community centers assisting Latina women. English and Spanish brochures on recipes including folate supplement, posters and folic acid curriculum were distributed. The goal for the educational events was to teach Latinas about the benefits of folic acid in preventing NTDs, the required time period for taking folic acid, sources of folic acid, and identification of folic acid on food labels and multivitamin bottles (Kannan et al., 2007). At the end of the educational sessions, 96% of participants stated that they had become aware that folic acid reduces the risk for NTDs and that they planned to consume more products containing folate supplements based on the information they got from the sessions (Kannan et al., 2007).

Statewide surveillance systems

Statewide surveillance systems to track individuals who are at a higher risk of NTD pregnancies and initiate periconceptional treatments have proven successful in reducing the incidence of neural tube defects in high- risk areas in the nation (Stevenson et al., 2000; Collins et al., 2011). For instance, a six-year study conducted between 1992 and 1998 in South Carolina, a state with high prevalence of NTDs, used patient genetic counseling data collected through surveillance systems to reduce the prevalence of spina bifida in that region (Stevenson et al., 2000). Before the study, the National Center for Health Statistics classified South Carolina as a region with high risk of NTDs due to its high prevalence of NTDs that was about twice the national prevalence rate (Stevenson et al., 2000).

Furthermore, active and passive surveillance systems were used to monitor at-risk pregnancies, in which active methods included the use of maternal serum alpha fetoprotein (MSAFP), a blood test that checks the level of protein AFP in pregnant women to determine risks for spina bifida and anencephaly (Dashe et al., 2006). Further active surveillance methods included prenatal diagnosis monitoring programs and pregnancy ultrasonography (Stevenson et al., 2000). Passive surveillance systems included medical records, physician reports, vital records review, and Center for Disease Control and Prevention (CDC) confirmation of cases (Stevenson et al., 2000). Participants consisted of 278,122 cases of NTDs for both live births and fetal deaths between 1992-1998 in South Carolina. Because at risk patients were examined and given appropriate doses of folic acid before and during pregnancy, the rate of NTDs declined from 1.89 to 0.95 cases per 1000 live births (Stevenson et al., 2000).

Additionally, cases of preconception folic acid supplementation increased from 8% (prior to the study), to 35% (after the study). Overall, this study shows that tracking high risk NTD pregnancies statewide through surveillance systems is successful in preventing the occurrence and recurrence of NTDs, due to immediate folic acid interventions in such regions (Collins et al., 2011; Dashe et al., 2006; Mosley et al., 2009; Stevenson et al., 2000).

Folic acid implementation: Correcting misinformation about its use

Since the national implementation of folic acid supplements in childbearing women and women wishing to get pregnant by the U.S. Preventive Services Task Force (USPSTF) in 1996, NTDs have been declining in the U.S. (Wolff, 2009). Although reports have emerged on the dangers of high level of folate in the body, studies have been done to discredit such information (Mills, 2017). Indeed, a study by Mills (2017) raises the issue of the continuing rise of NTDs in European countries due to their lack of any folate initiative from 1991 to 2011. Mills

(2017) explains that European countries are reluctant to implement a campaign similar to the one in the U.S. due to concerns about side effects such as cancer, asthma, twin pregnancies and anemia, as a result of consuming too much folate. Mills (2017) supports his argument for the implementation of folic acid supplementation through extensive studies that folate causes more benefits to pregnant women and their babies than harms. Furthermore, a study by Wolff (2009) ascertains through observational studies from 1995 (before the folate implementation) to 2008 that more evidence supports the USPSTF theory that folate supplement provides more benefits to pregnant women and their babies by reducing the risk of NTDs.

Prenatal surgery

Until recently, the majority of NTDs were only repaired after birth, but innovative progress in medicine permitted the disease to be treated prenatally, although disabilities such as neurological defects and hydrocephalus remain (Werner et al., 2012). However, when comparing both prenatal and postnatal surgical procedures to treat spina bifida, the literature presents benefits and drawbacks of both methods. Although the first is beneficial for the baby as he/she will have fewer lifelong consequences compared to the latter, it presents safety issues for the mother (Werner et al., 2012). Such issues include maternal risk of not having more children, but eventually the literature ascertains that further research is needed to find safety techniques to reduce such risks during the prenatal surgery procedure (Werner et al., 2012).

Studies on resistant folic acid methylation on mice

Another approach that researchers have looked at to prevent the development of NTDs is by studying the genetic role of resistant folic acid methylation. Researchers looked to explain why some women give birth to children with NTDs despite the fact that they are on folate supplement diets before and during pregnancy. As previously mentioned, the MTHFR gene

mutation is the cause and it ultimately leads to resistant folic acid methylation (Blom et al., 2006; Imbard et al., 2013). An attempt to repair this genetic malfunction in humans is done through studies on mice in which the direct supplementation of folate to nucleotides may have a positive impact of successfully closing neural tubes of the fetus (Leung et al., 2013). Such studies are successful on mice experimentation and the findings reveal a step forward in investigating direct folate supplement to nucleotides in order to prevent NTDs in humans.

Despite public health approaches to reduce the burden of NTDs in the U.S., there are still limitations on how to successfully eliminate non-genetic risk factors and improve quality of life of the patient (Valdez et al., 2016). Such limitations may be due to the fact that NTDs are rare diseases (affects less than 200,000 individuals in the U.S.), and that people affected with NTDs are scattered across the U.S. population (Valdez et al., 2016). These two factors may be the reason why public health approaches to tackle NTDs may be different from interventions used to control disease outbreaks (Valdez et al., 2016). Continuous research that highlights the limitations of public health methods on steps to further reduce the prevalence of the disease would be valuable to the population at risk. Recommendations that address social and health disparities, improve quality of life for those with NTDs, emphasize family support and advocate for more research are additional steps that would further reduce the burden of NTDs in the U.S.

Recommendations and solutions

The following recommendations would not only help the general population to acquire knowledge about the disease, but would also educate and possibly incite policymakers to develop steps necessary to prevent NTDs.

Address social disparities

Since it is noted that individuals who live in low socio-economic neighborhoods and those who work jobs that handle chemicals are at greater risk of having children with NTDs, recommendations focus on addressing social disparities among such demographic groups (Au et al., 2010; Lupo et al., 2012). Examining physical aspects in relation to housing quality, degree of overcrowding, environmental chemical exposures, violence, air pollution, green space and park availability, healthy food availability, and side walk access are crucial to understand if such physical states increase the risk factors for NTDs in disadvantaged neighborhoods. Addressing such issues would be one of several steps in educating and convincing policymakers to invest in developing better living conditions in such neighborhoods. However, in order to ensure that stakeholders are aware of the needs of individuals living in these areas, community leaders should remain proactive by communicating such information. In return, if improved living conditions decrease the prevalence of NTDs in such areas, non-genetics risk factors could significantly decrease. Assessing, implementing, and evaluating public health approaches and developing resources to assist parents in such areas could certainly contribute to reducing the prevalence of NTDs in such places.

Address health disparities: Monitor healthcare access in low income populations

In order to decrease the prevalence of NTDs in underprivileged communities, healthcare access is needed in such communities. Community leaders along with the population should monitor and evaluate the healthcare need of the entire community. They should present such findings to public health organizations and stakeholders so that people in the community would get the help they need. It is important to collect data to better identify and address disparities in such communities. This can be done by surveying the number of mothers who have access to prenatal care and those who have access to educational resources on healthy pregnancies. The

survey would be a good starting point to evaluate the medical and educational needs in such communities. If women have more access to prenatal care and receive educational resources to prevent NTDs, the overall rate of the disease could potentially decrease in such communities.

Improving quality of life for children living with neural tube defects: school integration systems

Specialized programs for children with NTDs to improve their learning skills would be a great tool in helping such children as they would be allowed to learn at their own pace. Such programs may be tailored to address the learning development of each child. Parents and teachers would need to collaborate on educational resources that work best for each child. These initiatives can be integrated in existing school programs. Besides specialized programs, it would be important to have children with NTDs interact with one another in the same classroom. Currently there are special education programs which involve inclusion with other children, however, inclusion with children who also have the same diagnosis could help get a sense of comfort. This may be done by designating a few schools within each district where this program would be implemented and children living in the areas could be assigned to such schools. This option compared to building new specialized schools for affected children is not only budget friendly for policymakers, but it would also improve quality of life among children with NTDs.

Because children with NTDs, especially those with spina bifida often find themselves isolated and unable to interact with their peers, it would be interesting to have them interact in their own environment within the classroom. Reaching out to peers who understand them at school could probably lead to the development of higher self-esteem at school, home and in the community. If these initiatives end up being successful, it would mean that communities will witness more people with NTDs developing self-confidence at their jobs. As a result,

communities could also experience better productivity coming from individuals affected by NTDs.

Family support

Another approach to reduce the burden of NTDs in our nation is to create health programs to counsel affected families on how to live with a child with disabilities. Quite often, we forget that parents with a disabled child may occasionally suffer from mental distress due to the stress associated with taking care of their child (Essner & Holmbeck, 2010). Mental health support for these families should be included in any healthcare budget. Parents of children with NTDs should be offered incentives and free counseling sessions in order to recharge their energy and keep a healthy family environment. In some other instances, siblings of the affected child should also receive counseling in order to understand what the affected child is going through as well as peer support groups. Understanding the different changes that will happen during the life cycle of the affected child can prevent any frustrations that may occur and emotionally prepare everyone in the family circle. Similarly, offering mental health support through funding for those living with NTDs is a great approach to help them interact with their peers.

Funding and research

More funding in research is needed to study the folic acid methylation process in humans. If this procedure is made possible and successful in humans, genetic risk factors for NTDs could tremendously decline. Furthermore, increased funding would allow researchers to find better methods to perform prenatal surgeries so that mothers would experience fewer complications later in life. If such methods are discovered through research, babies treated prenatally could

suffer less health outcomes and the cost related to hospitalizations could be tremendously reduced. Overall, funding is always needed for research on NTDs.

Successful evidence-based initiatives that may serve as examples to the aforementioned recommendations

Having some evidence-based initiatives to reduce disparities in underprivileged communities could be useful tools to implement in order to reduce the prevalence of NTDs in such communities. For instance, a study that focused on smoking cessation programs in an ethnic minority population owed its success on the entire community commitment and the involvement with stakeholders (Cooper et al., 2002). Researchers from the study created an advisory committee that included community leaders, government agencies, and advocacy, educational and consumer groups (Cooper et al., 2002). Together, members from the advisory committee provided feedback on the progression of the study and evaluated outcomes. They assessed and interpreted findings and guided researchers in decision making. Overall, creating an advisory committee in underprivileged communities was effective in narrowing the gap in health disparities (Cooper et al., 2002). This evidence based initiative can be applied to disadvantaged communities that have individuals with NTDs and experience social and health disparities. The success of such initiative would notice the decline of NTDs among such populations.

Additionally, a study that focused on mental health for siblings of children with cancer highlights that these siblings suffer high levels of psychological stress and adaptation (Sidhu et al., 2006). The study performed a therapeutic peer support camp for the siblings of children affected by cancer and the goal was to reduce stress level, improve social abilities, and increase knowledge on the impact of cancer and its treatment (Sidhu et al., 2006). At the end of the therapeutic intervention, it was noted that siblings who attended the camp session displayed

improved mental health (Sidhu et al., 2006). Such siblings also attended follow up sessions to maintain healthy mental health (Sidhu et al., 2006). This evidence based intervention can be applied when improving quality of life and family support of individuals who live with NTDs and their family members.

Conclusion

Neural tube defects are a preventable public health burden that affects about 3000 children in the United States of America. The most prominent form of NTDs is spina bifida and it is a condition that affects mostly Hispanic babies compared to non-Hispanic white and black (Kannan et al., 2007). Although research states that NTDs is a multifactorial disease, there is evidence that both genetic and non-genetic factors contribute to the development of NTDs. Genetic factors include the MTHFR gene mutation, while non-genetic factors include obesity, diabetes, low socio-economic status, insufficient folic acid supplement, both paternal and maternal occupations, maternal age environmental factors and folic acid antagonist medications (Levin & Varga, 2016; Lupo et al., 2012; Rasmussen et al., 2008). Though current interventions focus on folic acid implementation, education and awareness of the disease, and disease surveillance systems, there are still limitations that need to be addressed. Such limitations include addressing social and health disparities in disadvantaged neighborhoods, lack of resources to assist families and those affected with NTDs and the need for continuous research. Using evidence-based public health interventions is crucial in reducing the burden of NTDs in our nation.

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