Knowledge and use of folic acid supplementation: a study of Colorado women whose pregnancies were affected by a fetal neural tube defect

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Abstract

Objectives: To determine whether women who have had a pregnancy in which the fetus is affected by a neural tube defect (NTD) knew of current folic acid recommendations; whether the recommendations are followed before or during the pregnancy associated with an NTD and subsequent pregnancies; and to ensure that women who have had an NTD-affected pregnancy have access to proper information about NTDs and folic acid recommendations.

Methods: Women living in Colorado who had a pregnancy in 1996 or 1997 in which the fetus had an NTD were interviewed in 1998 about their knowledge and use of folic acid supplementation.

Results: Twenty-one of 42 eligible women were interviewed. All women first learned of the folic acid recommendations either during or after their affected pregnancy. Only 23.8% of the women took vitamins containing folic acid during the 1 to 3 months before becoming pregnant. None who had a subsequent pregnancy followed the recommendation to consume 4.0 mg/d of folic acid, beginning at least 1 month before conception. Women who had subsequent pregnancies became pregnant on average of 9 months after their affected pregnancy ended.

Conclusions: Most women who have an NTD-affected pregnancy are unaware of the national folic acid recommendations and do not follow these recommendations for subsequent pregnancies. However, such women are receptive to information about folic acid supplementation. Health care providers and public health officials should consider their role in assuring that education is provided in an effective and timely manner to women with NTD-affected pregnancies.

Résumé

Objectifs : Déterminer si les femmes qui ont porté un fœtus atteint d’une malformation du tube neural connaissent les recommandations actuelles au sujet de l’acide folique, vérifier si les recommandations ont été suivies avant ou pendant la grossesse où le fœtus présentait une malformation du tube neural et avant ou pendant les grossesses subséquentes, et veiller à ce que les femmes qui ont eu une grossesse avec malformation du tube neural du fœtus aient accès à des renseignements pertinents au sujet de ces anomalies et des recommandations relatives à l’acide folique.


Résultats : Des 42 femmes admissibles, 21 se sont prêtées à l’entrevue. Toutes les participantes ont d’abord entendu parler des recommandations relatives à l’acide folique pendant ou après leur grossesse où le fœtus était atteint d’une malformation du tube neural. Seulement...
Introduction

Neural tube defects (NTDs) are serious birth defects of the brain and spine. Each year in the United States, approximately 4000 pregnancies are associated with NTDs, which are major causes of perinatal, infant and childhood morbidity and mortality.

For many years it has been suspected that maternal diet and behaviour play a role in the health of an unborn child. The B vitamin folic acid, in particular, has been a major research focus in the study of NTDs. Research conducted in the 1980s and 1990s confirmed that periconceptional supplementation with either folic acid or a multivitamin preparation containing folic acid significantly reduces the occurrence of NTDs. A randomized, double-blind study published in 1991 demonstrated a 72% reduction in the recurrence of NTDs among women who consumed 4.0 mg/d of folic acid.

Women who have had a pregnancy in which the fetus had an NTD are at increased risk of having a subsequent pregnancy affected by an NTD. In 1991, the Centers for Disease Control and Prevention (CDC) recommended that such women should take 4.0 mg/d of folic acid when planning a pregnancy. Similarly, in 1992, the US Public Health Service recommended that all women who are capable of becoming pregnant should take 0.4 mg/d of folic acid to prevent the occurrence of NTDs. The US Food and Drug Administration required the addition of folic acid to the grain supply starting in 1998. This action is expected to reduce the occurrence of NTDs and to reduce the birth prevalence of NTDs by 18%. Therefore, officials still advise that women who are capable of becoming pregnant supplement their diets with folic acid.

Recent studies have shown that many women are unaware of these recommendations and that the majority of women do not consume the necessary dietary folic acid daily. Little information is available about whether the recommendations to prevent recurrence are being implemented.

We therefore carried out this study to determine whether women who have had an NTD-affected pregnancy know of the CDC and Public Health Service folic acid recommendations; to determine whether the recommendations had been followed before or during the NTD-affected pregnancy and subsequent pregnancies; and to insure that women who have had an NTD-affected pregnancy have access to proper information about NTDs and folic acid recommendations.

Methods

Women who had a pregnancy in which the fetus was affected by an NTD in 1996 and 1997 were identified through Colorado Responds to Children with Special Needs (CRCSN). CRCSN is the birth-defects monitoring program at the Colorado Department of Public Health and Environment. Case reports of NTDs are received from hospital discharge data, birth certificates, fetal death certificates, a spina bifida clinic and physicians. Medical records of reported cases were reviewed and the NTD diagnosis was confirmed before inclusion in the study.

A questionnaire was developed and administered by telephone in 1998 to women who had an affected pregnancy. The questionnaire was pilot-tested by interviewing local members of the Spina Bifida Association who had experienced an NTD-affected pregnancy. The questionnaire included questions about demographic characteristics, vitamin use before and during the affected pregnancy, whether a subsequent pregnancy had occurred, the vitamin use before and during that preg-
nancy, current vitamin use, birth control use, plans for
additional children and knowledge of folic acid recom-
mendations. Women were given an opportunity to
refuse to participate, via letter, before being contacted
by phone. For women whose primary language was
Spanish, interviews were conducted in Spanish.

In addition to asking about subsequent pregnan-
cies in the interview, Colorado vital records (birth
and fetal death certificates) were also searched
(through July 1999) to determine the birth date for
subsequent pregnancies of both interviewed and
noninterviewed women. CRCSN was used to deter-
mine if the subsequent pregnancy was diagnosed
with an NTD (through July 1999).

We used $t$-tests and $\chi^2$ analysis to compare demo-
graphic characteristics of the participants and non-
participants.\textsuperscript{14}

The specific amount of folic acid can vary among
multivitamins and prenatal vitamins; however, most
multivitamins contain 0.4 mg of folic acid.\textsuperscript{15} We
examined the folic acid content of 10 brands of pre-
natal vitamins and found that 9 contained 0.8 mg of
folic acid, so when a woman reported she had taken
a multivitamin or a prenatal vitamin, we assumed it
was the 0.8 mg amount.

**Results**

**Demographic characteristics of the study
population**

Forty-two women were identified as having a preg-
nancy ending in 1996 or 1997 in which the fetus was
affected by an NTD. Twenty-one women agreed to
participate in the study. Three women refused to
participate and 18 could not be contacted. Table 1
provides demographic information about the partici-
pants and the nonparticipants. There were no statisti-
cally significant differences in age, education or
racial distribution between the 2 groups.

**Summary of women interviewed**

Of the 21 NTD-affected pregnancies, 17 (81%) fetuses
were affected by spina bifida and 4 (19%) by anencephaly.
Five (24%) women had a pregnancy that resulted in
death of the newborn or fetus. None of the women
interviewed had had a previous NTD-
affected pregnancy.

Table 2 provides information on the women’s
knowledge of the folic acid recommendations. None
of the women heard of the recommendations prior to
their NTD-affected pregnancy. At the time of the in-
terview, the majority (76%) of the women had heard
of the Public Health Service’s folic acid recom-
dendations. The major source of the information was
a health care provider.

Table 3 provides information on the women’s be-
aviour regarding folic acid intake during their af-
ected pregnancy. Nineteen (90%) reported that they
took vitamins or supplements. Only 5 (24%) of
the women took vitamins containing folic acid during
the 1 to 3 months before becoming pregnant. Twelve
(57%) women were at least 6 weeks into pregnancy

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|c|}
\hline
\textbf{Characteristic} & \textbf{Participants, }$\ n = 21$ & \textbf{Nonparticipants, }$\ n = 21$ & \textbf{p value} \\
\hline
Age, yr & & & \\
\hline
\text{Mean} & 26 & 26 & 0.9* \\
\hline
\text{Range} & 18–35 & 17–43 & \\
\hline
Education — mean, yr & 12 & 12 & 0.8* \\
\hline
Race, no. (and %) & & & 0.5† \\
\hline
\text{Nonhispanic white} & 15 (71) & 12 (57) & \\
\hline
\text{Black} & 2 (10) & 1 (5) & \\
\hline
\text{Hispanic} & 4 (19) & 7 (33) & \\
\hline
\text{Native American} & 0 (0) & 1 (5) & \\
\hline
\end{tabular}
\caption{Demographic characteristics of the study population}
\end{table}

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|}
\hline
\textbf{Knowledge} & \textbf{No. (and %)} \\
\hline
\text{At time of interview} & \\
\text{Had not heard of folic acid recommendations} & 5 (24) \\
\text{Had heard of folic acid recommendations} & 16 (76) \\
\hline
\text{Source of knowledge} & \\
\text{Health care provider} & 11 (69) \\
\text{Medical clinic} & 2 (13) \\
\text{Media} & 3 (19) \\
\hline
\text{First heard of recommendations} & \\
\text{During affected pregnancy} & 4 (25) \\
\text{At child’s birth} & 6 (38) \\
\text{After child’s birth} & 5 (31) \\
\text{Did not know when she first heard} & 1 (6) \\
\hline
\end{tabular}
\caption{Knowledge of folic acid recommendations for the 21
mothers who had children with neural tube defects}
\end{table}
before they began to take supplements containing folic acid. Finally, 2 women (10%) could not remember when they began taking supplements containing folic acid and another 2 women (10%) did not take folic acid before or during their affected pregnancy.

At the time of the interview, 16 (76%) women reported that they were currently taking vitamin pills or supplements: of these 16, 2 (13%) were taking less than 0.4 mg/d; 7 (44%) were taking between 0.4 and 0.8 mg/d; 4 (25%) were taking between 0.9 and 1.6 mg/d; and 2 (13%) were taking 4.0 mg/d. One woman did not know how much or how frequently she was taking folic acid. Thus, 14 (67%) of the 21 women interviewed were taking at least 0.4 mg/d of folic acid at the time of the interview.

Thirteen (62%) women reported they were using some type of birth control at the time of the interview. Of those not using birth control (8), 1 was pregnant and 1 was planning a pregnancy. The woman who was pregnant at the time of the interview was taking between 0.9 and 1.6 mg/d of folic acid. The woman who was planning a pregnancy was taking 4.0 mg/d.

Of the 5 women who were not currently taking supplements at the time of the interview, 2 stated that their reason for not taking them was that they did not have any supplements. One woman felt that she did not need supplements, another stated that her body rejected them, and another was not sure why she did not take supplements.

Seventeen (81%) of the interviewed women requested and received additional written information about folic acid and NTDs.

**Summary of subsequent pregnancies**

Among the 42 eligible women there were 9 who had a pregnancy after their affected one. Of these 9 women, all had a live birth and none of the children were diagnosed with an NTD. The mean time between the birth of the index child and the birth of the subsequent child was 18 months (range from 11 to 28 months). Six of the 9 women were among those interviewed. Of the 6, 2 reported that they had taken a prenatal vitamin during the 1 to 3 months before becoming pregnant. The remaining 4 women started taking the vitamins after they were at least 3 weeks into pregnancy. The dose of folic acid taken by these women ranged from 0.8 to 2.4 mg/d. Two of the 6 women knew of the folic acid recommendations to prevent recurrence. They had heard of them at the time of birth of their affected child. However, only 1 took folic acid (2.4 mg/d) before conception of the subsequent pregnancy. The other woman was 8 weeks’ pregnant before she began taking folic acid (0.8 mg/d).

**Discussion**

None of the women in this study knew of the 1992 US Public Health Service’s folic acid recommendations before their NTD-affected pregnancy. Even then, none of the women who had a subsequent pregnancy followed the folic acid recommendations for women who have had an NTD-affected pregnancy. One woman who was planning a subsequent pregnancy was following these recommendations at the time of the interview.

Five (24%) of the women interviewed were taking daily supplements containing folic acid before they became pregnant with their NTD-affected pregnancy. The 1996 Colorado Behavioral Risk Factor Surveillance System survey found that 44% of Colorado women of childbearing age indicated that they were taking folic acid daily. A national survey in 1998 found that 32% of women of childbearing age reported daily intake of a vitamin supplement containing folic acid. Clearly, the majority of women in this study and in other studies are not following the Public Health Service’s folic acid recommendations.

It is alarming that none of the women who had a subsequent pregnancy followed the national health recommendations for folic acid ingestion. The majority of these women did not even know about the recommendations. In this study, the mean time between the birth of the index child and the subsequent child was 18 months. Assuming a full-term preg-
nancy, conception would occur on average 9 months after birth of the affected child and because NTDs occur very early in pregnancy, health care providers and public health professionals need to educate women soon after the NTD-affected pregnancy about preventing NTD in a subsequent pregnancy.

There were limitations to this study. First, only 21 women were interviewed out of the 42 women who were identified by CRCSN in 1996 and 1997. Although these data did not identify statistically significant demographic differences between participants and nonparticipants, there was a noteworthy difference in racial distribution. It is possible that the knowledge and behaviour of the participants may be significantly different from those of the nonparticipants. In addition, it may be difficult to generalize the results of this study to all women who are at increased risk for NTD-affected pregnancies, since only women who delivered a child with an NTD or experienced a fetal death were included in the study. Between 9% and 42% of pregnancies affected by NTDs are electively terminated when an NTD is diagnosed. Such cases were not included in this study. Lastly, the women were interviewed in 1998 about what they did before or during their pregnancies that took place in 1996 and 1997. It may have been difficult for many of these women to remember accurately what they did and what they knew.

Eighty-one percent of the women interviewed stated that they would like to receive written information about folic acid and NTDs. Health care providers and public health officials should consider their role in assuring that this desired education is provided in an effective, timely manner to women with NTD-affected pregnancies.

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References


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