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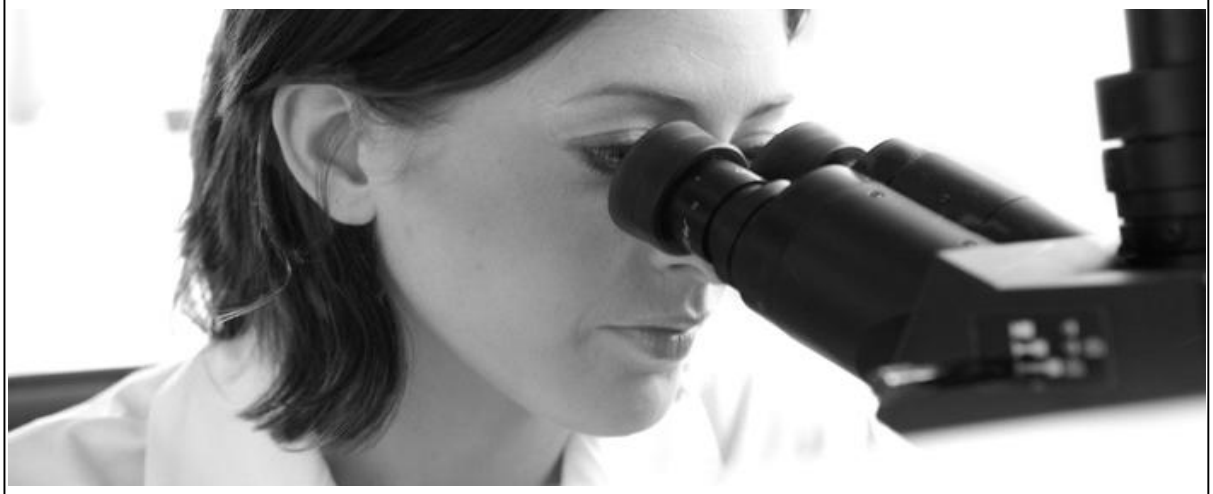

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RESEARCH ARTICLE

THE NEED OF IMPLEMENTING AN INTEGRATED APPROACH FOR THE PRIMARY PREVENTION OF NEURAL TUBE DEFECTS AND OROFACIAL CLEFTS IN D.R. CONGO: CHALLENGES AND OPPORTUNITIES

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ABSTRACT

The DR Congo is facing a great challenge in the implementation of folates supplementation among pregnant women for preventing anemia during pregnancy and congenital malformations, such as neural tube defects and orofacial clefts.
Indeed, 58.5 % of pregnant women are illiterate or with low level of literacy. The comparison between the instruction level and pregnancy planning demonstrated that there is a strong dependence of the instruction level on the pregnancy planning. This is graphically described as the curve of ALDEN
Several feeding diets among pregnant women are lacking in folates and others vitamins. The vast majority of pregnant women are fed by available diets in 72.5% despite their increased needs in folates and others vitamins.
Few pregnant women (9.2%) are attending antenatal care before the first trimester. However, the vast majority of pregnant women are attending antenatal care services later in 71.61%. The vast majority of women are getting pregnant without family planning in 82.0%.
Moreover, this study demonstrated clearly that vitamins supplementation is facing several challenges as follow: the insufficient level of instruction, lack of family planning, the delay to attend antenatal care service, inadequacy between evidence-based data and the actual supplementation DR Congolese programme and lack of integrated approach in the supplementation programme.
The results might offer more opportunities in primary prevention for sensitization of attending antenatal care services utilization as soon as possible, for strengthening the family planning programme, implementing preconceptional vitamins supplementation and the need of an integrated approach for the primary prevention of congenital malformations.

INTRODUCTION

In the past decades, congenital malformations, especially spina bifida and lip-palate clefts were considered rare or extremely rare. But Clefts of the lip (CL), the palate (CP), or both (CLP) are the most common orofacial congenital malformations found among live births, accounting for 65% of all head and neck anomalies. The frequency and pattern of orofacial clefts in different parts of the world and among different human groups varies widely.[1]

In Canada, the prevalence of neural tubes defects have been reduced from 11, 1/10000 (live births and early neonatal mortality) in 1989 to 5.6/10000 in 1999.Inversely,the prevalence of clefts ranged from 6.7/10000 in 1989 to 7.6/10000 in 1999[2].

Recent data describing the prevalence of neural tube defects (NTDs) in developing countries are both conflicting and sparse. As reported in several epidemiological surveys, the prevalence of NTDs was fairly high and varied in different parts of India (ranging from as low as 1.1/1000 live births in Kolkata to as high as 18/1000 live births in the state of Rajasthan). Another study, indicated that the prevalence of

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NTDs was 11.4/1000 live births in one of the areas of India. A study from China , showed that in the northern province of Hebei the rates of NTDs ranged from 5-6/1000 live births, whereas the rates were much lower (1/1000 live births) in the southern provinces of Zhejiang and Jiangsu.[3]

Table 1 Sociodemographic data

Sociodemographic data	N	IC 95%	%
Age			
13-18 years	82		18.0
19-24 years	166		36.5
25-30 years	108		23.7
31-36 years	69		15.2
37-42 years	24		5.3
>42 years	6		1.3
Gravidity			
Primigravida	144		31.6
Multigravida	233		51.3
>5 pregnancies	78		17.1
Marital status			
Singles	151		33.2
Married	302		66.4
Divorced	1		0.2
Widows	1		0.2
Level of instruction			
Illiterate	106		23.3
Primary	160		35.2
Secondary	176		38.7
Tertiary	13		2.9
Profession			
Farmers	221		48.6
Pupils	24		5.3
Vendors	21		4.6
Dressmakers	14		3.1
Teachers	9		2.5
Public workers	5		1.1
Nurses	3		0.7
Private accounters	3		0.7
Private pharmacists	2		0.4
Housewifes(Jobless)	152		33.4

In DR Congo, globally the national data regarding the prevalence of NTDs and clefts are not easily available or studies conducted to determine the prevalence at a national level are very extremely scarce. However there are data from some regions, mostly in the South-Eastern of DR Congo as follow:

1. In the past, two studies conducted in DRCongo have respectively found the prevalence rate of 0.67% in Lubumbashi and 1.2% in Kinshasa[4,5]
2. A study conducted in Lubumbashi found that the prevalence of NTDs (spina bifida) is 5.68/10000 and clefts is 6.49/10000 in 2011 in urban area[6]
3. A cross-sectional study conducted from November 2011 to March 2012 on a surgical campaign-based in Goma, DRCongo found that isolated cleft lip was the most common type (97.5%); it is unilateral in 81.9% of cases; incomplete (50.1%) and sitting on the left side (49.9%)[7]
4. Another campaign-based retrospective study conducted in Goma from January 2002 to May 2004 found that the more cleft extends from the superior lip to the palate through the alveolus, the more the frequency of the various types of clefts lips/palate decreases: 59.6% (simple clefts lip), 37.1% (labio-alveolar clefts), and 2.2% (cleft palate). The left incomplete cleft lip variety represents 33.7% of all varieties[8]
5. In 2015, a prospective multicenter study conducted in North & South Kivu Provinces in DR Congo found the prevalence malformations rate among 11,500 registered births of 0.89% in South Kivu and 0.64% in North-Kivu. The most encountered malformations were the musculoskeletal defects with 35.5% and the nervous system/neural tube defects with 30.8% [9]

The review of the literature showed that the occurrence of malformations, especially NTDs and orofacial clefts are evident and prevalent in different regions in DR Congo despite the lack of national data records, lack of surveillance system and lack of management resources.

Beyond the prevalence of occurrence among births of NTDs and clefts; the psychosocial effects on individuals and families are devastating and impacting negatively in the quality of life. These effects are ranging from maternal distress, anxiety, impairment of general wellbeing, etc.[10]

There are several lay-beliefs concerning these malformations due to vitamins deficiencies. Empirically, it has been mentioned that there are anthropological explanations to these malformations in D.R. Congolese communities. However, there are actually evidence-based data demonstrating that these malformations are due to vitamins' deficiencies and other factors, especially environmental and genetic.[11]

The vitamin's supplementation in D.R. Congo is mainly based on folates administration mixed with iron to prevent anemia occurring during pregnancy. The National Program of Reproductive Health recommends the supplementation of folates mixed with iron six weeks before the term pregnancy and six weeks after the delivery[12]. However this recommendation is poorly understood and its implementation is lacking among child-bearing women of several communities in D.R. Congo.

This study is conducted to [1] advocate the implementation of integrated approach for the primary prevention of NTDs and clefts, [2] to identify challenges of implementing the vitamins supplementation in women of child-bearing age at the Eastern of D.R. Congo

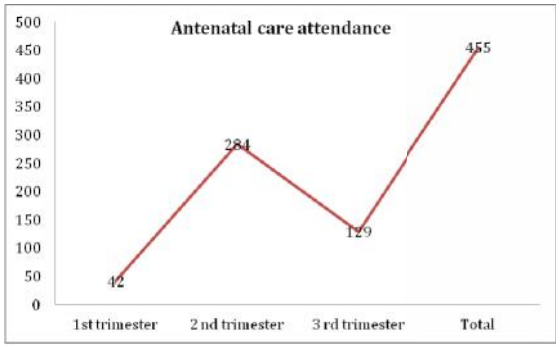
METHODS

A multicentre prospective study was conducted in four primary and secondary health care facilities at the North-Eastern of D.R. Congo during a four-week period (October 2013) and enrolled sequentially 455 pregnant women attending antenatal cares. Data were collected from these pregnant women using semi-structured questionnaire .The software SPSS 17.0 has been used for data analysis.

More than half of pregnancies occurred between 19-30 years with 60.2% (19-24 years with 36.5% and 24-30 years with 23.7%).The rate of pregnancies occurrence in pubescent and adolescents is 18.5%. More than half pregnant women are multigravida (2-5 pregnancies) with 53.3% compared to primigravida with 31.6%.The majority of pregnant women are

married with 66.4% compared to singles with 33.2%.The vast majority of pregnant women have been educated (73.9%) with 35.2% at a primary level and 38.7 % at a secondary level. The majority of pregnant women are farmers with 48.6% and jobless with 33.4%

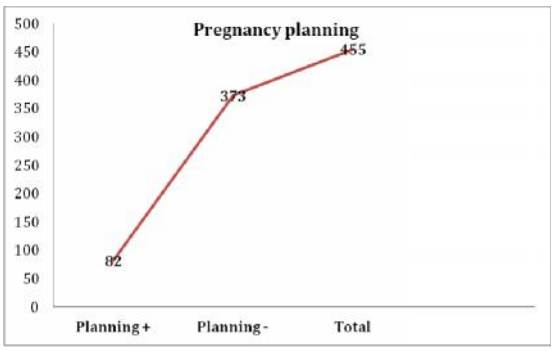
Antenatal care attendance



Graph 1 Gestational age for the antenatal car attendance

A few proportion of pregnant women is attending antenatal care at the first trimester with 9.2%

Pregnancy planning



Graph 2 Pregnancy planning

The vast majority of pregnant women did not plan the current pregnant with 82.0% (373)

Table 2 Usual diet among pregnant women

Usual diet	N	%
Rice + beens	5	1.1
Foufou[1] + greens	86	18.9
Beens + banana	1	0.2
Rice + beens	1	0.2
Beens + potato	1	0.2
Foufou + meat + greens	1	0.2
Foufou + beens	1	0.2
Beens + cassava leaves + foufou	29	6.4
No diet choices	330	72.5
Total	455	100

Usual diets

The vast majority of pregnant women do not have diet choices with 72.0 % eating what is available.

[1] Foufou is a kind of compact and consistent paste made locally from cassava flour.

Comparison between level of instruction and pregnancy planning

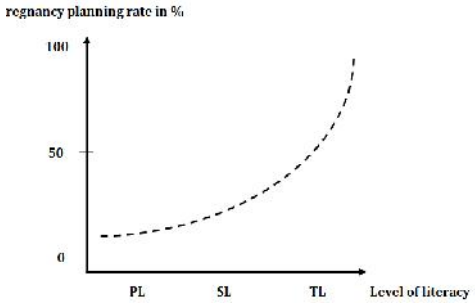
Among 106 (100%) illiterate pregnant women, 97(91.5%) did not plan the current pregnancy compared to those at tertiary level who did not plan current pregnancies with 53.9%. Moreover, 85 % of pregnant women at a primary level did not plan current pregnancies and 75% of pregnant women at secondary level did not plan their current pregnancy. This trend has been graphically named as the curve of ALDEN. The higher the literacy level is, lower the rate of unplanned pregnancy is. This tendency is described graphically by the curve named the curve of ALDEN.

Table 3 The comparison between level of instruction and pregnancy planning

Instruction/ pregnancy planning	Planning +	Planning -	Total
Illiteracy	9 (10.97%)	97 (26.00%)	106
Primary	24 (29.26%)	136 (36.46%)	160
Secondary	43 (52.43%)	133 (35.65%)	176
Tertiary	6 (7.31%)	7 (1.87%)	13
Total	82	373	455

Fisher's exact test is 0.0002 < P value < 0.001

The Fisher's exact test is 0.0002(< P value <0.001); therefore the difference is statistically significant. The pregnancy planning is very strongly depending on the level of instruction.



Graph 3 The curve of ALDEN

Legend:
PL: Primary level; SP: Secondary level; TL: Tertiary level

DISCUSSION

Antenatal care attendance

Most countries have policies and programs for prenatal iron-folic acid supplementation, but coverage remains low and little emphasis is placed on this intervention within efforts to strengthen antenatal care services[13].

In DR Congo, the programme of prenatal IFA (tablets) is based on the women attendance to the antenatal care where the rate is low and among attendees. Worldwide it has been demonstrated that the adherence rate is very low. Therefore the benefits of IFA are not at all tangible mainly in terms of anemia reduction rate in pregnancy[14]

The findings from this study indicated that a few proportion of pregnant women is attending antenatal care at the first trimester with 9.2% where IFA (Iron-Folic Acid) tablets are freely provided as a supplementation programme. The programme mainly focused on the prevention of anemia in pregnancy is totally inadequate when it comes to the primary prevention of NTDs (spina bifida) and orofacial clefts. In fact, the strong evidence has demonstrated that the daily use of IFA tablets and micronutrients at preconception and throughout the first trimester (the two first months of pregnancy) reduced the

occurrence and recurrence of NTDs by 72% in MRC study[8] and by 100% in a randomized clinical trial in Hungary[15]

Less than 10% of pregnant women are attending the antenatal care services in the first trimester in our study. All of them were non-adherent to IFA tablets based on the definition as pregnant mother is said to be non-adhered to iron/folate supplement if they took less than 65% of the supplement, equivalent to taking supplement less than 4 days a week[16]

Most NTDs (spina bifida, anencephaly, encephaloceles, meningoceles, etc) are as a result of defective closure of the neural tube during the 4 th week of development and the orofacial clefts during the 5 th and 6 th week of development [17] Therefore it's very late to commence the IFA tablets even in the end of first trimester as in the D.R. Congo programme where the vast majority (90.8%) attending the ANCs is during the second trimester (62.4%) and in the third trimester (28.4%) and the D.R. Congo programme will not primarily prevent against NTDs.

Even if the current D.R. Congo program was not firstly aimed to prevent against the NTDs and orofacial clefts, the D.R. Congo government should expand and update the existing programme to the prevention of NTDs and orofacial clefts including all others components as diversified food production and its access and utilization (nutrition), education and IFAs supplementation programmes for women of reproductive age as implemented in several countries in India, Egypt, Lao, Cambodia, Vietnam and Philippines[18]

The challenges at the Eastern D.R. Congo are as follow:

1. The very low attendance rate to the ANC services at the first trimester (9.2%)
2. The very low adherence rate to IFA tablets for ANC attendees for the prevention of anemia during pregnancy
3. The non-use of IFA tablets and micronutrients at preconception and throughout the first trimester for the primary prevention of NTDs and orofacial clefts.
4. The inadequacy of the current D.R. Congo IFA supplementation programme mainly focused on the prevention of anemia in pregnancy
5. The focus on women of reproductive age beyond the pregnant women

Mostly the DR Congo programme should focus efforts on the prevention due to its communities' inability to seek surgery care (access to health care due to its costs and scarcity of trained surgical team).This is attributable to two major reasons: the lack of financial resources (58.7%) and the lack of information (22.5%) [7]

Pregnancy planning & level of education

The unplanned pregnancy is a worldwide concern [19, 20, 21, 22]. A study in Canada stated that the supplementation of IFA is still problematic since 50% of pregnancies are unplanned[21] compared to 82.0%. Among 106 (100%) illiterate pregnant women, 97(91.5%) did not plan the current pregnancy compared to those at tertiary level who did not plan current pregnancies with 53.9%. Moreover, 85 % of pregnant women at a primary level did not plan current pregnancies and 75% of pregnant women at secondary level did not plan their current pregnancy.

The higher the literacy level is, lower the rate of unplanned pregnancy is. This trend is described graphically by a curve named the curve of ALDEN.

The Fisher's exact test is 0.0002(< P value <0.001); therefore the difference is statistically significant. The pregnancy planning is very strongly depending on the level of instruction. The challenges at this point are as follow:

1. The lack of education in health and others relevant issues within communities in the Eastern D.R. Congo
2. The high rate of unplanned or unintended pregnancies (82.0%)

Diets

The vast majority of pregnant women do not have diet choices with 72.0 % eating what is available. The two following categories are those consuming:

1. Cassava leaves, beans and foufou
2. Foufou and greens

The diets before and during the pregnancy period are very poor in terms of folates intakes based on Dietary Reference Intakes (DRIs) developed by the Food and Nutrition Board (FNB) at the Institute of Medicine (IOM) of the National Academies at the United States of America[23].

Folate is found naturally in a wide variety of foods, including vegetables (especially dark green leafy vegetables), fruits and fruit juices, nuts, beans, peas, dairy products, poultry and meat, eggs, seafood, and grains. Spinach, liver, yeast, asparagus, and Brussels sprouts are among the foods with the highest levels of folates[24, 25, 26, 27].

The challenges at this point are as follow:

1. The increase in diversified food production
2. The limited access to diversified food production
3. The limited utilization of diversified food(lack of nutrition education on Essential Nutrition Actions (ENA)
4. The lack of food bio-fortification

CONCLUSION

The DR Congo should make efforts to implement the integrated approach for the primary prevention of NTDs and orofacial clefts while focusing on the prevention of anemia in pregnancy, the education of communities, the improvement of antenatal care (ANC), the family planning and the diversified food utilization among communities.

Due to the size of the country and limited resources, the integrated approach should firstly be implemented in regions with high prevalence; this means that studies should be funded and effectively conducted to determine the regions where the prevalence is high.

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