Original Article

Applying a knowledge-to-action framework for primary prevention of spina bifida in tropical Africa

Kasereka M. Claude*, Kwibuka L. Juvenal* and Michael Hawkes†

*HEAL Africa, Goma, Democratic Republic of Congo, †University of Toronto, Ontario, Canada

Abstract

Maternal periconceptual folate supplementation reduces the incidence of neural tube defects; however, in settings where population-level food fortification is not available, it is not clear how best to promote this prevention strategy. Guided by a knowledge-to-action methodology, we used mixed quantitative and qualitative methods to define the local disease burden, then designed, implemented and evaluated a culturally tailored educational intervention in eastern Democratic Republic of Congo, where resource limitations and threats to human security contribute to restricted capacity for the prevention and management of congenital malformations. A descriptive case series of 27 patients undergoing surgery for spina bifida demonstrated a short-term mortality of 15% and long-term disability in survivors. A survey of knowledge, attitudes and practices demonstrated a low level of folate awareness (53%) among women of reproductive age. Focus group discussions revealed exotic aetiological views, significant gender issues and several barriers to folate use. A culturally tailored radio broadcast and an educational video were designed and produced locally based on qualitative and quantitative findings. Evaluation of the video documented high levels of viewer satisfaction and unequivocal knowledge gain ($P \leq 0.001$). We conclude that spina bifida poses a significant burden on affected patients and their families in the African context, but folate is underutilized as a prevention strategy. Patient education through video media results in increased awareness and understanding of spina bifida and folate, a first step in empowering women to reduce the risk of spina bifida in their children in the absence of population-wide food fortification.

Keywords: spina bifida, myelomeningocele, neural tube defect, folic acid, knowledge translation, Africa.

Correspondence: Michael Hawkes, University of Toronto, 10-401, 101 College St., Toronto, ON, Canada, M5S 1Y9. E-mail: michael.hawkes@utoronto.ca

Introduction

Spina bifida (spinal dysraphism, myelomeningocele) is a congenital malformation causing mortality or life-long disability, preventable by maternal folate supplementation in the periconceptual period (Pitkin 2007). Folate deficiency is prevalent among pregnant women in sub-Saharan Africa (Fleming *et al.* 1986; Coulibaly *et al.* 1987; Fuller *et al.* 1988; Mashako *et al.* 1991; Dop

et al. 1992; Massawe *et al.* 1999; Friis *et al.* 2001). Several descriptive case series of spina bifida in the African context have documented an incidence rate of 0.4–1.99/1000 births and have highlighted the need for periconceptual folate supplementation (Alatise *et al.* 2006; Ugwu *et al.* 2007; Komolafe *et al.* 2008; Njamnshi *et al.* 2008), but there are as yet few reports of attempts to promote this apparently straightforward strategy. Fortification of staple foods became

mandatory in the USA and Canada in 1998 and in South Africa in 2003, resulting in a 30–46% reduction in neural tube defects (De Wals *et al.* 2007; Sayed *et al.* 2008). However, in resource-poor areas where widespread food fortification programmes are not available, women in the periconceptual period need to be aware of the benefits of folate supplementation in order to avail themselves of this prevention strategy on an individual basis.

Health system capacity for the management of congenital anomalies such as spina bifida is frequently inadequate in resource-limited settings, and even routine primary care may be neglected in areas affected by violent conflict. The Democratic Republic of Congo (DRC) has been the stage of a decade-long civil and continental war, which has crippled health care infrastructure both for primary care as well as specialized paediatric services. One study has implicated civil conflict as a factor contributing to a rising incidence of congenital malformations in the DRC (Ahuka *et al.* 2006). Efforts to strengthen capacity for primary prevention of birth defects in this area are warranted.

To address the problem of spina bifida in eastern DRC, we employed a knowledge-to-action methodology (Straus *et al.*, 2009). Planned action theorists have described a knowledge-to-action cycle, whereby knowledge creation and application are related in an iterative, dynamic and complex process (Straus *et al.*, 2009). Following this framework, our aims were to: (1) define the burden of illness; (2) explore knowledge attitudes and practices relevant to spina bifida prevention within the local context and assess barriers to folate supplementation; (3) select and tailor educational interventions to the local context; and (4) monitor the effect of the intervention on knowledge use.

Materials and methods

Knowledge-to-action cycle

The overarching framework that guided our research methodology was the knowledge-to-action cycle (Graham *et al.* 2006; Straus *et al.*, 2009). Phases within this conceptual framework include identifying the problem; reviewing and selecting the knowledge to implement; adapting or customizing the knowledge to the local context; assessing the determinants of knowledge use; selecting, tailoring, implementing and monitoring interventions related to knowledge translation; evaluating outcomes or impacts of using the knowledge; and determining strategies for ensuring sustained use of knowledge. We began by reviewing the evidence that spina bifida is a preventable malformation, through the use of periconceptual maternal folate supplementation. We next documented the burden of illness through a review of surgical cases managed at the surgical referral hospital HEAL Africa in Goma, DRC. We then moved to examining barriers to prevention, using qualitative and quantitative methods. Guided by these findings, we devised and implemented educational interventions and assessed the impact of a knowledge translation strategy (educational video) on conceptual knowledge use. Additional steps in the knowledge translation cycle (evaluating outcomes and sustaining knowledge use) were beyond the scope of the present study.

Study site and population

HEAL Africa, a non-governmental organization and referral hospital in Goma, DRC, has provided surgical and medical services as well as social outreach to the vulnerable populations of eastern DRC throughout the civil war over the past decade, which has claimed

Key messages

- Spina bifida poses a significant burden on affected patients and their families in eastern Democratic Republic of Congo, but folate is underutilized as a prevention strategy.
- Patient education through video media results in increased awareness and understanding of spina bifida and folate.
- Although prevention of neural tube defects is challenging in the absence of population-wide food fortification, education represents a first step in empowering women to reduce the risk of spina bifida in their children.

the lives of an estimated 5.4 million people (Coghlan *et al.* 2009). Recognized for excellence in the surgical management of congenital malformations, HEAL Africa has a wide catchment area from the province of North Kivu. Study participants therefore came from Goma and surroundings as well as from remote sites as far as 800 km away.

Ethics approval was obtained from the medical directors of HEAL Africa and Matanda Hospitals. Participants for survey questionnaires were recruited from maternity clinics at HEAL Africa and Matanda hospitals (women attending routine prenatal care clinics). Consenting women completed survey questionnaires. For focus group discussions (FGDs), participants were recruited from previous surgical patients managed at HEAL Africa hospital, as well as their spouses and community members without an affected child. All focus group participants provided informed consent. For evaluation of the educational video, women were recruited from maternity clinics at HEAL Africa hospital. Consenting women completed a questionnaire, watched the video and completed a post-intervention questionnaire.

Descriptive case series

A retrospective chart review of cases of spina bifida undergoing surgery at HEAL Africa was conducted. Cases of isolated myelomeningocele operated between June 2006 and December 2007 were included; patients with co-existing malformations (e.g. talipes equinovarus) were excluded. Patient demographic information and short-term outcome (3 weeks postoperative) were abstracted and summarized. Given the large distance patients travelled for surgical care, long-term follow-up data were frequently not available.

Survey questionnaires

We assessed the knowledge, attitudes and practices relative to spina bifida and its prevention in a convenience sample of 150 women attending pre-natal consultations at HEAL Africa hospital and at Matanda Hospital in nearby Butembo. Women in this area typically attend two to three prenatal visits beginning at 3

months gestational age. We adapted a previously published questionnaire (Bener *et al.* 2006) to survey patient demographics, knowledge about spina bifida and folate, attitudes and practices related to vitamin supplementation between June and August 2007. Non-parametric descriptive statistics were used to summarize the data, and associations between folate awareness and education level and socio-economic status were assessed using the Mann–Whitney test.

FGDs

In order to complement quantitative information gathered through survey questionnaires, we also collected qualitative data using FGDs. FGD participants were drawn from key informant groups: mothers and fathers of affected children; and unaffected women and men of reproductive age in the community. A total of five FGDs were conducted: three consisted of women alone, and two involved both men and women, allowing for a dynamic exploration of gender issues (Table 1). FGDs were conducted in the local languages Swahili, Kinyarwanda and Lingala. Discussions were recorded on audio cassette for later verbatim transcription and translation into English. FGD questions were elastic, open-ended and probing, allowing participants to shape the discussion. In some instances, questions arising from previous focus groups were used to confirm prevalent views with different participants and to explore themes in greater depth. FGDs were continued until a point of saturation (when themes began to repeat themselves in the discussions). Transcripts were read by and discussed among research team members for thematic

Table 1. Focus group discussion participants

Focus group number	Number of female participants*	Number of male participants*
1	7 (3)	0
2	3 (3)	3 (3)
3	6 (4)	0
4	4 (0)	4 (0)
5	21 (0)	0

*Numbers in parentheses indicate number of participants who were parents of children with spina bifida.

content. Verbatim representative quotations as well as statements of particular interest were extracted and organized according to theme.

Evaluation of educational video

A locally produced educational video describing basic facts about spina bifida and folate was presented to 142 women of reproductive age attending pre-natal clinics at HEAL Africa hospital (Goma, December 2009). Participants completed questionnaires before and after viewing the video. Items on the questionnaires consisted of demographic information (before video), satisfaction questionnaire (five items evaluated using a five-point Likert scale, after video) and knowledge-testing questions (six multiple-choice-style items, before and after video). Descriptive statistics were used to summarize demographic information and satisfaction scores. For knowledge questions, McNemar's test was used to compare the proportion of correct answers for each item before and after viewing the video, and the total score (sum of correct answers for an individual participant) was compared before and after video viewing using the Wilcoxon signed ranks test.

Results

Identifying, reviewing and selecting knowledge

We began with a review of the literature for evidence of effectiveness of maternal folate consumption for the prevention of neural tube defects. A systematic review and meta-analysis including four randomized or quasi-randomized clinical trials involving 6425 women indicated that periconceptional folate supplementation has a strong protective effect against neural tube defects (relative risk, 0.28) (Lumley *et al.* 2001). Recent observational studies support previous evidence for effectiveness from randomized trials (Wolff *et al.* 2009). Following mandatory folate supplementation of cereal products in Canada in 1998, rates of neural tube defects fell by 46% (De Wals *et al.* 2007). Collectively, data from clinical trials, observational studies and population-wide supple-

mentation efforts have demonstrated a clear and potent protective effect of periconceptual folate supplementation.

Identifying the problem: case series of spina bifida in eastern DRC

Over an 18-month period, 27 cases of spina bifida were managed at HEAL Africa, a surgical reference hospital in Goma, DRC. Demographic information and patient outcome is given in Table 2. Of note, four patients (15%) died, and major morbidity (bowel and bladder abnormality, lower limb dysfunction) was observed in the remainder of patients. This observation, coupled with the known benefits of folate supplementation, prompted us to investigate methods of promoting folate as a prevention strategy in the local context.

Table 2. Characteristics of 27 cases of spina bifida undergoing surgery at HEAL Africa Hospital (June 2006–December 2007)

Characteristic	Value (<i>n</i> = 27)
Age (months), <i>n</i> (%)	
<1	3 (11)
2–12	16 (59)
13–24	7 (26)
>24	1 (4)
Sex, <i>n</i> (%) female	13 (48)
Maternal age, median (range)	30 (19–42)
Paternal age, median (range)	38 (27–47)
Number of siblings, median (range)	5 (1–12)
Distance travelled for surgical treatment (km), <i>n</i> (%)	
Goma	<5 4 (15)
Rutsuru	75 5 (19)
Masisi	90 5 (19)
Lubero	235 9 (33)
Butembo	310 1 (4)
Kamituga	450 1 (4)
Kindu	800 2 (7)
Complications	
Meningitis	2 (7)
Post-operative hydrocephalus*	3 (11)
Mortality†	4 (15)

*Requiring insertion of ventriculoperitoneal shunt. †Short-term follow-up outcome only was available given the large distance patients travelled for care. Two patients died of central nervous system infection and two died with post-operative hydrocephalus despite ventriculoperitoneal shunting.

Assessing barriers to knowledge use: folate awareness and prevention practices

We next examined community knowledge, attitudes and practices relevant to spina bifida prevention. An 18-item survey questionnaire was administered to 150 female participants at two sites in eastern DRC (Goma and Butembo). Demographic information for the sample is given in Table 3.

Only 53% of women had ever heard of folic acid (Table 3). Among those who were aware of folate, only 16% were able to correctly identify that it was useful for the prevention of spina bifida. Awareness of folic acid increased with education level ($P = 0.017$) and socio-economic status ($P = 0.048$).

Assessment of existing practices revealed that 64% of women never took a multivitamin, while 23% took vitamins during pregnancy and 9% took a daily vitamin supplement (Table 3). The majority of women (76%) were willing to take a vitamin for spina bifida

prevention, and 99% would be willing to pay the 5 congolese francs (US\$0.01) that a folate supplement would cost daily.

Qualitative methods: FGDs

As a complementary approach, we used qualitative methods to probe in greater depth the burden of illness associated with spina bifida, as well as knowledge, attitudes and practices relevant to its prevention. FGDs with key informants generated the following themes: heavy psychosocial burden on affected families; exotic etiologic views not linked to folate consumption; general endorsement of a prevention strategy using folate; potential barriers to folate uptake. Representative quotations are provided for illustration.

Beyond the mortality and physical handicap associated with spina bifida (Table 2), profound psychosocial consequences were recognized. Mothers of affected children expressed strong negative emotional reactions to the birth of a child with spina bifida: *'I was in total shock, in despair. I prayed that the Lord would have pity on me and send a doctor able to take care of my child.'* Others had experienced major social consequences after the birth of an affected child: *'My husband abandoned me as soon as we got to the hospital. It's very difficult and painful to give birth to a malformed child.'* One male participant noted the stigma associated with a congenital malformation: *'Often the whole family is ridiculed, everyone in the village speaks ill of you. You get lots of advice, and even the father has no peace because of the child.'* One participant noted that a child with a congenital malformation may represent the lost expectation of a normal pregnancy outcome: *'To carry a pregnancy to nine months is not an easy thing. That is why we prepare ourselves seriously for delivery; it is an event. The mother is waiting for something good. Imagine if it is a child with spina bifida, how traumatic for the woman, what a curse! It is worrisome, stressful.'* Psychosocial consequences may represent an underappreciated burden over and above the mortality, long-term physical morbidity and financial costs associated with spina bifida in the African context.

Table 3. Knowledge, attitudes and practices relevant to spina bifida and its prevention among women attending prenatal clinics in eastern DRC

Characteristic	Value (n = 150)
Age, median (range)	26 (14–43)
Marital status, n (%)	
Married	109 (73)
Unmarried	41 (27)
Parity, median (range)	2 (0–13)
Education, n (%)	
No schooling	14 (9)
Primary	57 (38)
Secondary	52 (35)
University	27 (18)
Ever heard of folate, n (%)	80 (53)
Source of information about folate, n (%)*	
Doctor	24 (33)
Nurse	39 (54)
Pharmacist	3 (4.2)
Family/friends	4 (5.6)
Journal/book	1 (1.4)
Television/radio	1 (1.4)
Vitamin use, n (%)	
Never	99 (66)
During pregnancy	36 (24)
Daily	15 (10)

*Among women who had heard of folate. DRC, Democratic Republic of Congo.

Recognizing the causal link between nutritional factors and spina bifida may be an important determinant of willingness to take a folate supplement for prophylaxis. We probed participant knowledge of the causes of spina bifida. Some participants invoked supernatural forces: *'When a barren women who wants to have a child at all costs visits a fetishist, who sticks a malformation to her'; 'People think that it's witchcraft, but I think it's a disease like any other, or else that it's God's will.'* Others associated it with environmental factors including the ongoing violent conflict in the area, deficiency of female reproductive capacity or infection (associated with the notion that the illness might be vaccine-preventable): *'People say all sorts of things. I was convinced, having been told so by the medical staff, that spina bifida was the result of the polluted air due to firearms, and the war'; 'Some [midwives] say that we should have a tubal ligation because this is a strong sign that our female organs and our fertility are getting old'; 'An infection; negligence, that is, not having all the laboratory tests recommended during the antenatal clinic visits'; 'Others say that this malformation occurs because the mother of the infant drank dirty water, unfit for consumption'; 'I think that you, the medical expert, should have pity on us. Come up with a vaccine that we can take before pregnancy.'* Few identified nutritional or genetic factors as the principal determinants of spina bifida. This knowledge gap should be taken into account when promoting folate for spina bifida prevention.

After learning of the role of folate in spina bifida prevention, participants were generally very enthusiastic about its use: *'I beg you to help us with this medication to avoid giving birth to a child with spina bifida, which for us is a catastrophe'; 'This is very interesting. Truly, these mothers suffer alot to raise these children [with spina bifida] and if there is a product to prevent spina bifida, why not take it?'*

On the other hand, several important barriers were identified. Despite its low cost, daily folate consumption may pose a substantial financial burden on families in a region where extreme poverty is prevalent: *'Finances, because we come from villages ravaged by the war. Even a fifth of a dollar is a heavy cost for us.'* Because folate needs to be taken in the periconceptual period before neural tube closure and often

before pregnancy is recognized, folate supplementation is indicated for women contemplating pregnancy. FGD participants noted that many pregnancies in eastern DRC are unplanned and recognized that folate would need to be taken for the entire duration of a woman's reproductive years for maximum effectiveness. This represents a significant pill burden that decreased the acceptability of the intervention: *'Taking a medicine every day for my whole life, I couldn't do it, particularly because of the nausea it gives me.'* The participation of male household members, who often control household resources, was recognized as a potential barrier: *'(the men) need to agree first since they are the ones that give us the money. If they refuse, the process is blocked'; 'My husband knows that I only give birth to healthy children, and if I tell him today that I need to take a medication to prevent a malformation that doesn't exist in our family, it's strange, it's hard to understand.'* Male focus group participants were generally tolerant of the idea of folate supplementation for their wives, although some expressed surprising reservations: *'It is not a problem if this treatment doesn't interfere with sexual relations with our wives'; 'For me, there is no problem when my wife is pregnant, but I don't think it's necessary to take a medication when she is not pregnant.'*

Selecting, tailoring and implementing interventions

Taken together, these quantitative and qualitative data pointed to a significant physical and psychosocial burden of illness, as well as a remediable knowledge gap regarding the role of folate in spina bifida prevention. Lack of awareness of folate was felt to be the key barrier to folate use and was chosen as the target of a knowledge translation intervention to increase conceptual knowledge use. We therefore designed educational interventions aimed to increase the awareness of spina bifida and the beneficial role of folate supplementation. This strategy was further justified by the general acceptability of folate supplementation, its established use in the DRC as a pre-natal vitamin and resource limitations that were prohibitive for population-level folate fortification of food products.

Key messages included spina bifida as an uncommon but serious malformation with lifelong consequences for the child and family, benefit of folate in preventing spina bifida and the timing of folate during the periconceptual period for maximal efficacy. The relevant stakeholders targeted were women of reproductive age, as well as health-care practitioners that counsel pregnant women.

We used radio broadcasts and an educational video to increase awareness of spina bifida. These media were chosen based on potential for outreach (many more households own radio compared with television in this area), and because video format is engaging for participants and amenable to repeated presentation to small target audiences (e.g. maternity clinics). Radio broadcast consisted of a 45-min dramatization with a phone-in question and answer session, presented four times over a period of 1 month to an area covering an estimated population of 800 000. A Swahili-language video with French subtitles was produced and edited locally, incorporating the key messages.

Monitoring knowledge use: evaluation of educational video

In order to evaluate the effect of the educational intervention on women's knowledge about spina bifida and its prevention, we studied satisfaction and knowledge gain among women of reproductive age, a key target group for the prevention message. A total of 142 women attending prenatal consultations evaluated the video and answered knowledge-testing questions before and after viewing the video. Demographic information for the sample of women is given in Table 4. Participant satisfaction with the video is displayed in Fig. 1. Participants rated the video very favourably, with more than 95% of participants agreeing or strongly agreeing that the video was understandable, clear, enjoyable, dealt with an important topic and should be widely disseminated. Short-term knowledge gain was demonstrated comparing pre- and post-test scores on six questions related to spina bifida and its prevention with folate. For each of the six items, the proportion of correct answers increased

Table 4. Demographic characteristics of participants who evaluated the spina bifida instructional video

Characteristic	Value (<i>n</i> = 142)
Age, median (range)	23 (14–40)
Marital status, <i>n</i> (%)	
Married	108 (76)
Unmarried	34 (24)
Parity, median (range)	2 (0–8)
Education, <i>n</i> (%)	
No schooling	5 (4)
Primary	25 (17)
Secondary	81 (58)
University	31 (22)

significantly after viewing the video (Fig. 2, $P \leq 0.001$ for all items), as did the total score ($P < 0.0001$).

Discussion

Folate supplementation in the periconceptual period is an inexpensive and well-tolerated strategy for the prevention of spina bifida. Here, we report findings from a knowledge-to-action program to increase awareness of spina bifida and folate in tropical Africa.

This work was guided by planned action theory, following the knowledge translation framework of Graham and colleagues (Graham & Tetroe 2007). Phases included (1) a descriptive series of 27 cases of spina bifida and qualitative description of the psychosocial burden of illness (problem identification); (2) survey questionnaires and FGDs to determine local knowledge, attitudes and practices (customizing the knowledge to the local context); (3) educational messages in the form of radio broadcasts and a video (knowledge translation intervention) and (4) evaluation of the video by key informants (evaluating outcomes and impacts).

This study is remarkable for its setting in post-war DRC, where violent conflict and ongoing threats to human security have severely impaired health-care delivery (Coghlan *et al.* 2006; Coghlan *et al.* 2009). Congenital malformations including spina bifida are neglected diseases in this context, but represent nonetheless a significant physical and psychosocial burden of illness, as illustrated by our case series and FGDs.

Fig. 1. Participant satisfaction with educational video. Agreement with five statements (five-point Likert scale) is shown graphically, with $\geq 95\%$ of viewers agreeing or strongly agreeing that the video was understandable, clear, important, enjoyable and worth disseminating ($n = 142$ women attending prenatal clinics).

Fig. 2. Proportion of correct answers related to spina bifida and folate before (grey bars) and after (black bars) viewing educational video ($n = 142$ women attending prenatal clinics). Each question (answer) consisted of a stem with three to five detractors (multiple choice). Changes in proportion of correct answers were statistically significant for all six items (McNemar's test, $P \leq 0.001$), as well as for the sum of correct answers (Wilcoxon signed ranks test, $P < 0.0001$).

Our case series highlights the significant mortality and disability associated with spina bifida, as well as resource limitations for management of spina bifida in the area, as patients came from sites as far as 800 km away to receive surgical care. Other case series from Africa have reported similar findings, with incidence of spina bifida of 0.4–1.99/1000 births, and case fatality rates of 13–23% (Alatise *et al.* 2006; Ugwu *et al.* 2007; Njamnshi *et al.* 2008). We were not able to compute an incidence rate given the lack of reliable data for births within the wide catchment area and the likelihood of incomplete case detection.

Survey questionnaires of reproductive-age women attending pre-natal consultation clinics indicated that

only half of participants had ever heard of folate, and of those who had, only 16% recognized its role in spina bifida prevention. Education level and socio-economic status were determinants of awareness. Surveys from other geographic areas show similar levels of folate awareness, varying from 41% to 85% depending on the country (Wild *et al.* 1996; McGovern *et al.* 1997; Sayers *et al.* 1997; Kloeblen 1999; Morin *et al.* 2002; Abdulrazzaq *et al.* 2003; Amitai *et al.* 2004; Bener *et al.* 2006). There are opportunities for increased use of multivitamins and/or folate, because only 23% of women took a vitamin in pregnancy and 9% took a daily vitamin supplement. These figures are comparable to studies from the USA, Israel and

Qatar, which showed periconceptual folate use between 20% and 30% (Kloeblen 1999; Amitai *et al.* 2004; Bener *et al.* 2006).

Qualitative data from FGDs provided a rich picture of the lived experience of families and communities affected by spina bifida in tropical Africa. Previous studies based in developed countries as well as sub-Saharan Africa have described quality of life and disability in spina bifida patients (Cate *et al.* 2002; van't Veer *et al.* 2008) and have similarly observed prevailing folk religious beliefs, social stigma and threats to household stability as a result of a child with spina bifida (Oyewole *et al.* 1985; Alatisie *et al.* 2006). FGDs supported the acceptability of folate as a prevention strategy, notwithstanding predicted barriers to routine use of folate by expectant mothers (cost, pill burden, lack of family planning, need for support from male heads of households). In addition, exotic views of the causes of spina bifida emerged (supernatural forces, effect of violent conflict, infection), which should be considered in an educational intervention promoting folate; prior understanding of nutritional etiologic factors should not be assumed. Moreover, gender issues surfaced, particularly in FGDs involving both men and women. The views expressed appeared to indicate that women generally bear the chief responsibility of producing healthy children, whereas the role of men is more restricted, aloof and supportive. This was recognized by participants as a potential barrier to folate use, inasmuch as men often control household resources but may be less inclined to actively participate in promoting infant health. Men therefore represent an important target group for spina bifida education, as for other maternal-child health issues (Bajunirwe & Muzoora 2005).

Educational interventions including radio broadcasts and a video were designed, produced and edited locally in two of the regional languages (Swahili with French subtitles). Content was informed by qualitative and quantitative data related to local knowledge, attitudes and practices. A similar strategy has been employed to develop a culturally tailored video to address health-related behaviours in Chinese women in the USA (Wang *et al.* 2008). These were popular with viewers/listeners, as reflected by high satisfaction

ratings of the video by women attending prenatal clinics. Unequivocal knowledge gain was documented comparing responses to questions pertaining to spina bifida and its prevention before and after viewing the video.

Use of the knowledge-to-action cycle guided our research efforts and provided a unifying framework for presentation of mixed qualitative and quantitative methods to address several related but distinct research questions. Furthermore, the knowledge-to-action cycle situates our work within a broader goal of knowledge translation for preventing neural tube defects, which also includes measuring and sustaining the impact of interventions, as well as identifying new research questions. With its emphasis on adapting knowledge to the local context, the knowledge-to-action cycle may be particularly relevant to implementation of health care interventions in African settings.

Limitations of the current study include the small number of cases and short-term follow-up of patients in the case series, reliance on participant self-report for survey questionnaires and potential 'social courtesy bias' in participant satisfaction ratings of the video. With regard to the elements of the knowledge translation cycle, this study is limited in scope to identifying a problem; reviewing and selecting knowledge to implement; assessing barriers to knowledge use; selecting, tailoring and implementing an intervention; and monitoring knowledge use in the short term; it did not address other elements such as evaluating the impact or sustainability of the intervention. Change in spina bifida incidence (impact of the knowledge translation intervention) in the long term would also be a desirable outcome to measure. Cultural factors, which likely influenced qualitative data, may limit study generalizability to other contexts in Africa and beyond. Measures taken to ensure rigorous qualitative data collection included taping of FGDs with subsequent transcription and translation for thematic analysis. For quantitative data, use of a previously published questionnaire allows our results to be compared to previous work in the field.

Future directions for this work include a planned prospective analysis of spina bifida incidence within the hospital catchment area, which will provide base-

line data to investigate the impact of educational interventions. We are exploring innovative strategies to supplement food sources with folate at the regional level (flour and milled grain) and ways of targeting men in folate promotion for maternal–child health.

Acknowledgements

We wish to thank the Canadian Coalition for Global Health Research, whose 4th Summer Institute, as well as mentors within the organization, equipped us with the tools (research-to-action methodology) and principles (equitable research partnerships in global health) to carry this project to completion.

Source of funding

Salary support for KMC and KLJ was provided by HEAL Africa. Salary support for MH was provided by the Canadian Institutes for Health Research (CIHR) Clinician–Scientist Training Award.

Conflicts of interest

The authors declare that they have no conflicts of interest.

References

- Abdulrazzaq Y.M., Al-Gazali L.I., Bener A., Hossein M., Verghese M., Dawodu A. *et al.* (2003) Folic acid awareness and intake survey in the United Arab Emirates. *Reproduction Toxicology* **17**, 171–176.
- Ahuka O.L., Toko R.M., Omanga F.U. & Tshimpanga B.J. (2006) Congenital malformations in the North-Eastern Democratic Republic of Congo during Civil War. *East African Medical Journal* **83**, 95–99.
- Alatise O.I., Adeolu A.A., Komolafe E.O., Adejuyigbe O. & Sowande O.A. (2006) Pattern and factors affecting management outcome of spina bifida cystica in Ile-Ife, Nigeria. *Pediatric Neurosurgery* **42**, 277–283.
- Amitai Y., Fisher N., Haringman M., Meiraz H., Baram N. & Leventhal A. (2004) Increased awareness, knowledge and utilization of preconceptional folic acid in Israel following a national campaign. *Preventive Medicine* **39**, 731–737.
- Bajunirwe F. & Muzoora M. (2005) Barriers to the implementation of programs for the prevention of mother-to-child transmission of HIV: a cross-sectional survey in rural and urban Uganda. *AIDS Research Therapy* **2**, 10.
- Bener A., Al Maadid M.G., Al-Bast D.A. & Al-Marri S. (2006) Maternal knowledge, attitude and practice on folic acid intake among Arabian Qatari women. *Reproduction Toxicology* **21**, 21–25.
- Cate I.M., Kennedy C. & Stevenson J. (2002) Disability and quality of life in spina bifida and hydrocephalus. *Developmental Medicine Child Neurology* **44**, 317–322.
- Coghlan B., Brennan R.J., Ngoy P., Dofara D., Otto B., Clements M. *et al.* (2006) Mortality in the Democratic Republic of Congo: a nationwide survey. *Lancet* **367**, 44–51.
- Coghlan B., Ngoy P., Mulumba F., Hardy C., Bemo V.N., Stewart T. *et al.* (2009) Update on mortality in the Democratic Republic of Congo: results from a third nationwide survey. *Disaster Medicine Public Health Preparation* **3**, 88–96.
- Coulibaly M., Costagliola D., Zittoun J. & Mary J.Y. (1987) Modifications of hemato-biological parameters in pregnant women in a migrating population in northern Cameroon: prevalence of anemia, iron and folates deficiencies. *International Journal for Vitamin Nutrition Research* **57**, 173–178.
- De Wals P., Tairou F., Van Allen M.I., Uh S.H., Lowry R.B., Sibbald B. *et al.* (2007) Reduction in neural-tube defects after folic acid fortification in Canada. *The New England Journal of Medicine* **357**, 135–142.
- Dop M.C., Blot I., Dyck J.L., Assimadi K., Hodonou A.K. & Doh A. (1992) Anemia at delivery in Lome (Togo): prevalence, risk factors and consequences in newborn infants. *Revue d'Epidemiologie et de Sante Publique* **40**, 259–267.
- Fleming A.F., Ghatoura G.B., Harrison K.A., Briggs N.D. & Dunn D.T. (1986) The prevention of anaemia in pregnancy in primigravidae in the guinea savanna of Nigeria. *Annals of Tropical Medicine Parasitology* **80**, 211–233.
- Friis H., Gomo E., Koestel P., Ndhlovu P., Nyazema N., Krarup H. *et al.* (2001) HIV and other predictors of serum folate, serum ferritin, and hemoglobin in pregnancy: a cross-sectional study in Zimbabwe. *The American Journal of Clinical Nutrition* **73**, 1066–1073.
- Fuller N.J., Bates C.J., Hayes R.J., Bradley A.K., Greenwood A.M., Tulloch S. *et al.* (1988) The effects of anti-malarials and folate supplements on haematological indices and red cell folate levels in Gambian children. *Annals of Tropical Paediatrics* **8**, 61–67.
- Graham I.D., Logan J., Harrison M.B., Straus S.E., Tetroe J., Caswell W. *et al.* (2006) Lost in knowledge translation: time for a map? *The Journal of Continuing Education Health Professions* **26**, 13–24.
- Graham I.D. & Tetroe J. (2007) Some theoretical underpinnings of knowledge translation. *Academy of Emergency Medicine* **14**, 936–941.

- Kloeblen A.S. (1999) Folate knowledge, intake from fortified grain products, and periconceptional supplementation patterns of a sample of low-income pregnant women according to the Health Belief Model. *Journal of the American Dietetic Association* **99**, 33–38.
- Komolafe E.O., Komolafe M.A. & Adeolu A.A. (2008) Factors implicated for late presentations of gross congenital anomaly of the nervous system in a developing nation. *British Journal of Neurosurgery* **22**, 764–768.
- Lumley J., Watson L., Watson M. & Bower C. (2001) Periconceptional supplementation with folate and/or multivitamins for preventing neural tube defects. *Cochrane Database of Systematic Reviews*, (3) CD001056.
- Mashako L., Preziosi P., Nsibu C., Galan P., Kapongo C., Potier de Courcy G. *et al.* (1991) Iron and folate status in Zairian mothers and their newborns. *Annals of Nutrition & Metabolism* **35**, 309–314.
- Massawe S.N., Urassa E.N., Mmari M., Ronquist G., Lindmark G. & Nystrom L. (1999) The complexity of pregnancy anemia in Dar-es-Salaam. *Gynecology Obstetrics and Investigation* **47**, 76–82.
- McGovern E., Moss H., Grewal G., Taylor A., Bjornsson S. & Pell J. (1997) Factors affecting the use of folic acid supplements in pregnant women in Glasgow. *The British Journal of General Practice* **47**, 635–637.
- Morin P., De Wals P., St-Cyr-Tribble D., Niyonsenga T. & Payette H. (2002) Pregnancy planning: a determinant of folic acid supplements use for the primary prevention of neural tube defects. *Canadian Journal of Public Health* **93**, 259–263.
- Njamnshi A.K., Djientcheu Vde P., Lekoubou A., Guemse M., Obama M.T., Mbu R. *et al.* (2008) Neural tube defects are rare among black Americans but not in sub-Saharan black Africans: the case of Yaounde – Cameroon. *Journal of Neurological Sciences* **270**, 13–17.
- Oyewole A., Adeloye A. & Adeyokunnu A.A. (1985) Psychosocial and cultural factors associated with the management of spina bifida cystica in Nigeria. *Developmental Medicine Child Neurology* **27**, 498–503.
- Pitkin R.M. (2007) Folate and neural tube defects. *The American Journal of Clinical Nutrition* **85**, 285S–288S.
- Sayed A.R., Bourne D., Pattinson R., Nixon J. & Henderson B. (2008) Decline in the prevalence of neural tube defects following folic acid fortification and its cost-benefit in South Africa. *Birth Defects Research Part A Clinical and Molecular Teratology* **82**, 211–216.
- Sayers G.M., Hughes N., Scallan E. & Johnson Z. (1997) A survey of knowledge and use of folic acid among women of child-bearing age in Dublin. *Journal of Public Health Medicine* **19**, 328–332.
- Straus S.E., Tetroe J. & Graham I. (2009) Defining knowledge translation. *CMAJ* **181**, 165–168.
- Ugwu R.O., Eneh A.U. & Orumabo R.S. (2007) Neural tube defects in a university teaching hospital in southern Nigeria: trends and outcome. *Nigerian Journal of Medicine* **16**, 368–371.
- van't Veer T., Meester H., Poenaru D., Kogei A., Augenstein K. & Bransford R. (2008) Quality of life for families with spina bifida in Kenya. *Tropical Doctor* **38**, 160–162.
- Wang J.H., Liang W., Schwartz M.D., Lee M.M., Kreling B. & Mandelblatt J.S. (2008) Development and evaluation of a culturally tailored educational video: changing breast cancer-related behaviors in Chinese women. *Health Education Behavior* **35**, 806–820.
- Wild J., Schorah C.J., Maude K. & Levene M.I. (1996) Folate intake in young women and their knowledge of preconceptional folate supplementation to prevent neural tube defects. *European Journal of Obstetrics Gynecology and Reproductive Biology* **70**, 185–189.
- Wolff T., Witkop C.T., Miller T. & Syed S.B. (2009) Folic acid supplementation for the prevention of neural tube defects: an update of the evidence for the U.S. Preventive Services Task Force. *Annals of Internal Medicine* **150**, 632–639.