

# The treatment gap and primary health care for people with epilepsy in rural Gambia

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**Objective** To study primary-level management for people with epilepsy in rural Gambia by means of community surveys.

**Methods** After population screening was carried out, visits were made by a physician who described the epidemiology of epilepsy and its management. Gaps between required management and applied management were investigated by conducting interviews and discussions with people with epilepsy and their communities.

**Findings** The lifetime prevalence of epilepsy was 4.9/1000 and the continuous treatment rate was less than 10%. The choice of treatment was shaped by beliefs in an external spiritual cause of epilepsy and was commonly expected to be curative but not preventive. Treatment rarely led to the control of seizures, although when control was achieved, the level of community acceptance of people with epilepsy increased. Every person with epilepsy had sought traditional treatment. Of the 69 people with active epilepsy, 42 (61%) said they would like to receive preventive biomedical treatment if it were available in their local community. Key programme factors included the local provision of effective treatment and community information with, in parallel, clarification of the use of preventive treatment and genuine integration with current traditional sources of treatment and advice.

**Conclusion** Primary-level management of epilepsy could be integrated into a chronic disease programme covering hypertension, diabetes, asthma and mental health. Initial diagnosis and prescribing could take place away from the periphery but recurrent dispensing would be conducted locally. Probable epilepsy etiologies suggest that there is scope for primary prevention through the strengthening of maternal and child health services.

**Keywords** Epilepsy/epidemiology/therapy; Seizures/therapy; Patient acceptance of health care/ethnology; Attitude/ethnology; Choice behavior; Primary health care; Medicine, Traditional; Gambia (*source: MeSH, NLM*).

**Mots clés** Epilepsie/épidémiologie/thérapeutique; Crise/thérapeutique; Acceptation des soins/éthnologie; Attitude/éthnologie; Comportement choix; Programme soins courants; Médecine traditionnelle; Gambie (*source: MeSH, INSERM*).

**Palabras clave** Epilepsia/epidemiología/terapia; Ataques/terapia; Aceptación de la atención de salud/etnología; Actitud/etnología; Conducta de elección; Atención primaria de salud; Medicina tradicional; Gambia (*fuentes: DeCS, BIREME*).

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## Introduction

There are more than 50 million people with epilepsy worldwide but comprehensive or effective treatment is rare (1). It is estimated that more than 80% of people with epilepsy in developing countries do not receive effective treatment (2). Epilepsy is associated with psychosocial problems, reduced life expectancy, social isolation and an increased risk of unexpected death (3–6). The difference between the need for effective treatment and the receipt of such treatment is termed the treatment gap.

Seizures can be controlled in as many as 75% of people with epilepsy by means of inexpensive medication dispensed by primary health care workers (7, 8). Improved access to effective low-cost medication is essential if the uptake of treatment is to be increased. However, epilepsy has relatively complex social and spiritual implications, and the wide treatment gap is associated with varied combinations of factors other than cost and the provision of health care of good quality. Ideas about the causes of epilepsy and opinions about

treatment are often based on beliefs about disease, contagion and sources of unexplained phenomena. Since epilepsy is often seen as a spiritual affliction, some people with active epilepsy or their carers assume that traditional treatment in the local community is appropriate. Others, however, travel far and pay large sums in a quest for curative treatment but do not consider preventive biomedical medication to be appropriate (9, 10). Persons who experience infrequent attacks may only seek treatment when seizures occur. Those who seek biomedical care may be disappointed if clinic staff or medication are not available. How can these factors be confronted?

In the developing world there are a few sites where the prevalence of epilepsy is unusually high, but in most places an intervention programme isolated from primary care in general would be unjustifiable (11, 12). The purpose of the present study was to contribute to a comprehensive epilepsy programme within the primary health care system of the Gambia by providing information on the epidemiology of epilepsy, prevalent notions about the disease, and choice and

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experience of different treatments. By combining such information with existing knowledge it becomes possible to suggest ways of improving prevention, community acceptance and the uptake of effective treatment by persons requesting it as well as those who are unaware that they may benefit from it.

## Methods

### Study population

The 16 200 people who live in 40 of the villages around the town of Farafenni have been under continuous demographic surveillance by the Medical Research Council of the Gambia since 1981 (13). Under the Household Registration System, field workers gather information on residents, births, deaths and migration every three months. The majority of the people are involved in subsistence farming. For nearly half of the population the annual income is less than US\$ 150. The literacy rate among women is 3%. Islam is the religion of 95% of the population and there is a dense intermingling of religious and traditional medical systems. Many traditional healers are also religious elders.

In the surveillance area there are two primary health care dispensaries, one hospital and several private pharmacies, each with an intermittent supply of phenobarbitone. Transportation to these facilities is mainly by donkey or horse cart, and there are taxis on the few laterite roads. The six mobile maternal and child health clinics do not cater for chronic conditions. There are two cadres of community health workers: village health workers and community health nurses. The village health workers, based in villages with populations of more than 400, treat common conditions, including malaria, diarrhoea and acute chest infections, and provide some health information. They are supervised by the community health nurses. None of these health workers carry out treatment for chronic conditions.

### Surveys

The epilepsy surveys were linked to projects already in progress under the Household Registration System, in order to make the best possible use of resources. The first survey was conducted from January to June 1997 as part of a community noncommunicable diseases survey of persons aged over 14 years in a random selection of half the villages covered by the Household Registration System. The second survey, which took place between January and March 1999, was performed by field workers in all the demographic surveillance villages, and information was obtained on all household members from the heads of households. The participants in the noncommunicable diseases survey ( $n = 3223$ ) were therefore a subset of the population participating in the Household Registration System ( $n = 16\ 200$ ).

In both surveys a two-stage approach was used to identify people with epilepsy. In the first stage a screening questionnaire was employed, which was a modified version of one validated in Ecuador (14). For the survey under the Household Registration System a question was added in which local terms, determined by forward and back translation in the three local languages of Wolof, Mandinka and Fula, were used for types of seizure (15). Local validation of the questionnaires involved testing with known epileptics. In the second stage of both surveys, those people with a positive screening questionnaire were evaluated by a physician with neurological

experience. On the basis of histories taken from the study subjects or their close companions, epilepsy status was defined as active, inactive or a false positive screening test (i.e. not actually epileptic) and attempts were made to identify the forms of seizure. Information about treatment that had been tried was obtained for all people found to have active epilepsy and their attitudes were canvassed on the regular use of an effective medication available either at clinics or from community health workers.

People with active epilepsy were offered treatment with phenytoin in accordance with the government recommendations of the time. However, most were later given phenobarbitone, the supply of which was more secure in the country's primary care system.

A semistructured interview was conducted with 25% of the people identified as having active or inactive epilepsy, covering knowledge and beliefs about causation, treatment, health-seeking behaviour and experience, socioeconomic circumstances, relatives with epilepsy and possible etiological factors. Each interview was conducted by a trained Gambian field worker who was fluent in the local language and was supervised by the principal investigator. Predetermined open questions were used. Another trained Gambian field worker provided concurrent translation for the principal investigator, who could thus ask additional questions if clarification was needed. The same field worker conducted group discussions with the communities to which people with epilepsy belonged and with other interest groups, including teachers, religious leaders, traditional healers and biomedical health care workers. These discussions supplemented the interviews and established connections for the later dissemination of results. The field worker had been trained in group discussion techniques and was guided by an outline of topics to be covered after the following questions had been asked: "What can anyone say about epilepsy?" and "What can anyone say about how it is to be a person with epilepsy?" Again there was concurrent translation for the principal investigator, who answered questions about epilepsy after the discussion.

### Definitions

The standard criteria were used for the diagnosis and classification of epilepsy (16), on the basis of history and eyewitness accounts. No electroencephalogram facilities were available. Active epilepsy included any case of epilepsy in which there had been at least one unprovoked seizure in the previous five years, whether or not treatment was being given. Epilepsy was defined as inactive if there had been no seizure in the previous five years. Lifetime epilepsy was the sum of active and inactive epilepsy. Single or febrile seizures and acute symptomatic seizures were not included.

The etiology of the epilepsy was attributed to antenatal or perinatal insult if there was evidence from history or examination of static retardation of motor and/or mental development, with no obvious postnatal precipitating factor that was said to have been evident in the first year of life (17). Treatments labelled "traditional" and "biomedical" respectively refer to those originating from within a set of cultural beliefs and those based on a biomedical model.

### Analysis

Because of the erratic availability of drugs and the variability of attendance at clinics, many people with epilepsy used

biomedical medication only when seizures occurred and could not be classed as fully on or off such treatment. For data entry and analysis a score was given in order to code awareness of biomedical treatment, any persistent effort made to use it, and whether it was sought only at the time of a seizure or not at all. Replies concerning attitudes to the taking of preventive treatment locally were graded according to the proposed uptake from either of the dispensing sources (community health workers and clinics).

The survey data were analysed by means of Epi Info version 6. The interviews and group discussions were analysed by theme. Themes were considered across interviews and discussions and for relevance to understanding and responding to the wide treatment gap. Only statements or ideas expressed more than once are reported.

## Results

### Epidemiology

The compliance rates with the noncommunicable diseases survey and the Household Registration System survey were 81.7% and 99.8% respectively. Taken together, these surveys gave a prevalence of active epilepsy of 4.3/1000 (69/16 200) with a 95% confidence interval of 3.8–4.8, and a lifetime prevalence of 4.9/1000 (80/16 200) with a 95% confidence interval of 4.5–5.3. Common seizure types were primary generalized tonic-clonic and partial with secondary generalization, affecting 48% and 36% of lifetime epileptics respectively. Other partial seizures included complex partial and simple partial (6% and 2% of all seizures); primary generalized nonconvulsive seizures accounted for the remaining 8%. In persons with active epilepsy, age-specific prevalence peaked between 25 and 44 years (Table 1). Their frequency of fits ranged from daily to less than yearly, and was said to be declining for 36% of them; 26% said they were having seizures at least once a week.

In those people with a lifetime history of epilepsy for whom it was possible to suggest an etiology (55/80, i.e. 67% of all lifetime epileptics), 31% of seizures began after a febrile illness in childhood and for 67% there was evidence of antenatal or perinatal brain insult. Three people with epilepsy claimed to have first-degree relatives who were epileptics.

In the two years between the noncommunicable diseases survey and the Household Registration System survey, 3 people died among the 21 with lifetime epilepsy in the former survey. If, on average, they died halfway between the two surveys, there would have been 39 person-years of observation, giving a death rate of 77/1000 person-years. In the same period, 52 non-epileptic adults in the noncommunicable diseases population died in 6267 person-years of observation, resulting in a significantly lower death rate of 8/1000 person years ( $P < 0.005$ ). The three people with epilepsy who died were men with active epilepsy who were aged 24, 30 and 34 years. Verbal autopsy indicated that two of the deaths were caused by chest infections. One of these could have been tuberculosis but the carer sought traditional treatment because he had been disappointed previously when seeking seizure treatment at a clinic. The third death, which was not witnessed, was that of a fisherman who was found dead, tangled in his nets in shallow water.

Table 1. Age-specific prevalence of people with active epilepsy in the general population, the Gambia ( $n = 16\ 200$ )

Age (years)	Number with active epilepsy	Age-specific prevalence $n/1000$
< 15	18	2.4
15–24	20	6.6
25–34	11	7.2
35–44	11	7.5
45–54	2	1.8
55–64	4	4.7
65–74	3	4.3
<b>Total</b>	<b>69</b>	<b>4.3</b>

### Treatment

Every person with a lifetime history of epilepsy had used traditional treatment, and 74% had attempted to find treatment from more than one source. The median number of people from whom treatment had been requested was six (range 2–16). For nearly half of the people with active epilepsy this included a trial of biomedical treatment, either dispensed during the noncommunicable diseases survey or obtained by visiting a clinic.

Both traditional and biomedical methods of treatment were used preventively only on rare occasions. Only 16% (11/69) of people with active epilepsy knew that preventive treatment was possible. Attempts to obtain preventive treatment from a clinic were intermittently thwarted either by a lack of personal finances or by inadequate drug supplies. Consequently, the only people on regular treatment were those who had resorted to buying it from private pharmacies. Others who were currently seeking treatment attempted to find it only at the time of a seizure. Of the 48% (33/69) of people with active epilepsy who had never sought biomedical treatment, 70% did not know that clinics offered treatment for seizures. None of them said they would take regular preventive medication from a clinic but 45% (15/33) claimed they would take such medication if it were available from a community health worker. Given that 11 people were attempting to maintain preventive treatment at a clinic and that others had previously sought biomedical treatment only at the time of a seizure but now claimed that they would take continuous preventive treatment, the possibility existed that 61% (42/69) of people with active epilepsy could receive preventive treatment if it were available from a local community health worker. The remaining 39% (27/69) of people with active epilepsy said they would continue with no treatment or with traditional or biomedical treatment only at the time of a seizure, even if preventive medication were available locally (Table 2).

Most traditional treatment was obtained in the home villages from the healers, including relatives, who were used for other illnesses, or from healers visiting the villages. A person with epilepsy could attend the healer in person or send a representative to describe the symptoms and return with a treatment. Treatment included readings from the Koran, sometimes written down and sewn into cloth or leather amulets (jujus) that had to be worn. Water with herbs was

Table 2. Current treatment choices for people with active epilepsy, the Gambia ( $n = 69$ )

Current treatment choices of people with active epilepsy $n = 69$
<b>No treatment</b> $n = 6$ (8.7) <sup>a</sup> $n = 2^b$ (2.9) $n = 4^c$ (5.8)
<b>Traditional treatment only</b> $n = 27$ (39.1) $n = 8^b$ (11.6) $n = 19^c$ (27.5)
<b>Biomedical treatment when seizure occurs</b> $n = 23$ (33.3)
<b>Attempts made to obtain preventive biomedical treatment</b> $n = 11$ (15.9)
<b>Current treatment unknown/not available</b> $n = 2$ (2.9)

<sup>a</sup> Figures in parentheses are percentages.

<sup>b</sup> Aware of biomedical treatment.

<sup>c</sup> Unaware of biomedical treatment.

blessed and given for washing and drinking, sometimes combined with exorcism rituals. It was commonly considered that whether or not effective treatment was found was God's will, and that many people with different skills should therefore be visited in order to find a cure.

Except for treatment in the home villages the mean time taken to obtain treatment was six hours and the mean cost was 20 dalassi (US\$ 1.60) per treatment. No persons with epilepsy and none of their families put money aside to pay for treatment. When the time for repeat treatment came, or when a person with epilepsy had a seizure, the action taken depended on what resources were available. It was the duty of the relatives to pay for treatment.

### Context of epilepsy

The cause, persistence and treatment of epilepsy were accepted as ultimately under God's will and power. Most people attributed the immediate cause of epilepsy to a malign spirit but a few did not propose a cause. Some personal behaviour was thought to increase vulnerability to epilepsy, such as bathing late at night or the collection of water after dark by pregnant women. The avoidance of such behaviour was considered to offer the only possibility of prevention. Seizures were not seen as punishment, and no overt blame was attached to persons with epilepsy or their families. There was a generally high level of acceptance and integration of people with the disorder, but the degree of seizure control determined specific views and limitations on appropriate treatment, education and social roles. All the people with epilepsy in this rural area were living in a family setting, sometimes placing a heavy burden of care on their female relatives.

### Discussion

People with epilepsy in the Gambia may not attain their full potential because of a combination of low awareness and poor availability of effective treatment, frequent associated mental disability and limiting societal perceptions. The highly increased risk of early death in people with active epilepsy (4, 6) was demonstrated in this small sample. The prevalence figures for active epilepsy and the spontaneous decrease in the frequency of fits were in keeping with previous estimates (18),

although for lifetime epilepsy the figures were lower than would have been expected in the light of data from other studies. This might have been attributable to bias in recall, i.e. forgetfulness and denial, together with the high mortality rate (19). The types of seizure were defined as accurately as possible on the basis of eyewitness accounts but without the benefit of electroencephalograms (16). An attempt was made to fit a seizure type to each description that was felt to be a genuine case of epilepsy. It appeared that complex partial seizures were underrepresented but that generalized non-convulsive seizures were overreported, possibly because of misclassification of complex partial non-convulsive episodes (2).

The low continuous treatment rate, i.e. below 10%, is surprising but not unexpected and is similar to that reported elsewhere, e.g. in Sierra Leone (20). Increasing the sustained use of effective treatment is closely linked to improved awareness of epilepsy, as beliefs and explanations about epilepsy influence health-seeking and treatment-seeking behaviour. In many parts of sub-Saharan Africa, notions about epilepsy are rooted not in a medical model but in a spiritual model (21). This involves an external factor and the aim of the person with epilepsy is therefore to find a contextually relevant cure that removes the alien factor from the body. Consequently, preventive or biomedical treatment may not be seen as an option. Yet people with epilepsy sought treatment from various sources, often local, returned to the same healer if they were helped, and could be motivated by the community integration that accompanied seizure control. This presents an opportunity to increase understanding of preventive treatment and improve access to it locally. Already 61% were saying that they would take treatment from community health workers and more could be expected to follow suit if this were seen to be effective (2, 21).

The level of acceptance given to people with epilepsy depended mainly on the control of seizures and the severity of any mental handicap. Attitudes varied with previous experience of people with epilepsy. Many people recognized that their understanding of epilepsy was imperfect and that they were just trying to interpret their own experience as well as possible. A similar finding was reported from East Africa (21). Thus there was scope for influencing attitudes and improving the acceptance and treatment of people with epilepsy.

On the basis of our findings the following points seem relevant to community epilepsy programmes.

- The integration of people with epilepsy into communities can only be improved in parallel with improved seizure control.
- It is necessary to explain about preventive treatment in a way that is sensitive to prevalent perceptions and beliefs.
- Treatment should be provided locally by members of the community.

A combination of broadening current primary health care work and collaborating with new partners is required. The strengthening of primary care for other chronic conditions, including hypertension, diabetes, asthma and mental illness is already a priority because of the increasing burden of chronic diseases (11). Epilepsy could be integrated into this endeavour. The initial assessment, diagnosis and prescription could take place during focused visits by trained staff, including community nurses. Protocols would be required for prescribing a limited number of drugs with secure availability.

Prescribed drugs, held by community health workers, would be dispensed monthly to named patients. If the community health workers were able to provide effective treatment and make appropriate referrals they would be respected and their health education and information messages would be more likely to be heeded. The long-term presence of a primary care service for people with epilepsy in the United Republic of Tanzania changed notions about the illness and attitudes towards these people (4).

Collaboration with traditional healers would amount to an acknowledgement that biomedical services did not answer all the needs of people with epilepsy. Some healers would consider linking with biomedical services for the purposes of referral but would not countenance the sharing of ideas on treatment. The careful development of such a link would bring opportunities to present ideas about causation and preventive treatment without disturbing fundamental beliefs and values.

The prevention of onset of epilepsy depends on the risk factors. A putative etiology was defined for 67% of people with epilepsy, mostly on a basis of clinically obvious retardation of mental or physical development. If the 31% attributed to febrile illness represented overreporting, this would reflect people's need to construct a meaningful explanation for epilepsy. However, this can only be tested prospectively. Overall there is evidence of a significant role of insults that occur *in utero*, birth trauma and infectious diseases of childhood. In the study villages, home births without any trained supervision accounted for 48% of deliveries (22), and malaria and meningitis are common. Neurocysticercosis was an unlikely cause of epilepsy in this predominantly Muslim culture and no pigs were kept in the villages visited. The further refining of etiological data is not needed for an effective prevention programme, since the strengthening of primary maternal and child health services would automatically address much of the preventable causation of epilepsy (18).

It would not be easy to fund such a chronic disease programme, especially in the face of many competing health needs. With a revolving drug fund, payment for medication by

people with epilepsy would have to be made to a secure local committee or else centrally on an annual basis. This would relieve community health workers from the need to handle money, which might compromise their safety or be squandered. People with epilepsy are not usually in a position to organize themselves and put pressure on health services to provide appropriate treatment or improve primary prevention. The same is true for people with other chronic conditions. It is necessary for health care planners to be proactive in discussing the development of such programmes.

## Conclusion

The treatment gap for epilepsy in developing countries can be expected to diminish when effective and appropriately presented treatment is a real option. Similar issues exist for other chronic diseases. Tackling them all in an integrated primary care programme would form a systematic approach with an increased chance of sustainability. This would involve strengthening and mobilizing all primary care workers and recognizing traditional health and belief systems. If the treatment of epilepsy is not systematic and comprehensive it cannot be regarded as adequate (23). ■

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## Résumé

### Insuffisance du traitement et soins de santé primaires pour les personnes atteintes d'épilepsie dans des zones rurales de Gambie

**Objectif** Etudier, au moyen d'enquêtes en communauté, la prise en charge de l'épilepsie au niveau des soins de santé primaires dans des zones rurales de Gambie.

**Méthodes** Après un dépistage dans la population, des visites ont été faites par un médecin qui a décrit l'épidémiologie de l'épilepsie et sa prise en charge. Les écarts entre la prise en charge nécessaire et la prise en charge effective ont fait l'objet d'une investigation au moyen d'entretiens avec les personnes concernées et de discussions de groupe au sein de la communauté.

**Résultats** La prévalence de l'épilepsie sur la vie entière était de 4,9/1000 et le taux de traitement continu était inférieur à 10 %. Le choix du traitement était guidé par la croyance en une cause extérieure, surnaturelle, de l'épilepsie et le but recherché était curatif plutôt que préventif. Le traitement permettait rarement de maîtriser les convulsions, mais lorsqu'il y parvenait, les personnes épileptiques étaient mieux acceptées par la communauté. Toutes les personnes atteintes avaient cherché à se soigner par des

méthodes traditionnelles. Parmi les 69 personnes souffrant d'épilepsie active, 42 (61 %) ont déclaré qu'elles souhaiteraient recevoir un traitement biomédical préventif si cela était possible dans leur communauté. Les facteurs clés du programme prévoient la fourniture locale d'un traitement efficace et l'information de la communauté, avec en parallèle des explications sur l'utilisation du traitement préventif et une réelle intégration parmi les sources traditionnelles de traitement et de conseil.

**Conclusion** La prise en charge de l'épilepsie au niveau des soins de santé primaires pourrait être intégrée dans un programme de lutte contre les maladies chroniques portant sur l'hypertension, le diabète, l'asthme et la santé mentale. Le diagnostic et la prescription initiale pourraient avoir lieu loin de la périphérie, mais les renouvellements pourraient être faits au niveau local. Compte tenu des étiologies probables de l'épilepsie, une prévention primaire pourrait être envisagée par le biais d'un renforcement des services de santé maternelle et infantile.

## Resumen

### Fallos de la cobertura terapéutica y atención primaria para las personas con epilepsia en zonas rurales de Gambia

**Objetivo** Estudiar mediante encuestas comunitarias el tratamiento dispensado a las personas afectadas de epilepsia en el ámbito de la atención primaria en las zonas rurales de Gambia.

**Métodos** Tras llevar a cabo un cribado de la población, se realizaron visitas en las que un médico describía la epidemiología de la epilepsia y su tratamiento. Se investigó la divergencia entre el tratamiento requerido y el aplicado, organizando para ello entrevistas y charlas con las personas afectadas y sus comunidades.

**Resultados** La prevalencia de la epilepsia a lo largo de la vida era de 4,9/1000, y la tasa de tratamiento continuado era inferior al 10%. El tratamiento elegido respondía a la creencia en una causa espiritual externa de la enfermedad, y por lo común pretendía ser curativo, no preventivo. El tratamiento rara vez permitía controlar los ataques, pero cuando así ocurría el nivel de aceptación de las personas afectadas por parte de la comunidad aumentaba. Todos los aquejados de epilepsia habían buscado tratamiento tradicional.

De las 69 personas con epilepsia activa, 42 (61%) manifestaron su deseo de recibir tratamiento biomédico preventivo en caso de poder obtenerlo en su comunidad local. Entre los factores programáticos clave, cabe citar el suministro local de tratamiento eficaz e información comunitaria y, paralelamente, la aclaración del uso del tratamiento preventivo y una verdadera integración con las actuales fuentes tradicionales de tratamiento y asesoramiento.

**Conclusión** El tratamiento de la epilepsia en el nivel de atención primaria podría integrarse en un programa de lucha contra las enfermedades crónicas que cubriese la hipertensión, la diabetes, el asma y las enfermedades mentales. El diagnóstico y la prescripción iniciales podrían tener lugar fuera de la periferia, pero la dispensación periódica de tratamiento se realizaría a nivel local. Las etiologías más probables de la epilepsia permiten pensar que hay margen para reforzar la prevención primaria mediante el fortalecimiento de los servicios de salud maternoinfantil.

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