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Mobilization for cervical cancer screening: lessons from a poor-urban Yoruba community in Nigeria

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Summary
Cervical cancer is a major public health problem worldwide and it remains one of the commonest malignancies in Nigeria. Screening remains the most effective tool for the detection of Prc-invasive stages of cervical cancer, giving the opportunity for prompt and effective treatment before the emergence of invasive disease. In Nigeria, as in most developing countries, the concept of screening for cancer and its pre-emptive treatment is underdeveloped. The fact that the facilities and logistics for cervical cancer screening are generally located in the hospital setting, a place where one goes when ill, according to local beliefs, makes acceptance more difficult. That Nigeria urgently needs to set up or develop cervical screening programmes that will reach women outside the hospital setting in a culturally acceptable milieu is not in doubt. A community cervical screening survey for the prevalence of cervical intraepithelial neoplasia and HPV infection was initiated in Idikan, a poor-urban inner core area of Ibadan. The challenges and experiences encountered in the execution of the project which could serve as useful knowledge to those undertaking similar exercises, requiring mass mobilization for cancer screening of an uninformed group, are highlighted. Our experience in the course of this study is important as it brought out the probable influences of community dynamics and social organization in illness decisions and prescriptions for health operative in this particular population group. Cervical cancer screening programmes should therefore make provisions to accommodate the occasional outcomes as we had encountered. In addition, screening programmes in developing societies would require sensitive designs that should address the cultural attitudes, personal conflicts, expectations of treatment and overall context of preventive care.

Keywords: *Cervical cancer, screening programmes, cultural beliefs and attitude, acceptance*

Rdsumd
Lc cancer cervical est un problème de la santépubJic majeur mondial ct il reste un des malignités *le* plus commun au *Nigeria. Lc depistage* restes un moyen *lc plus efficacc* pour *la découvcrtc* d'étapes du cancer cervical, donnant /'occasion *pour une* traitement efficace avant Tapparition de la maladic invasive. Au Nigeria, comme dans la plupart des pays en voie de ddveloppcmcnt, le concept de depistage du cancer et son traitement préventif est sous-développé. Le fait que les installations et le logistique pour le depistage du cancer cervical sont gdnéralement situees a l'hopital ou se trouvent les malades d'apres les croyances locales le rend difficile de P accepter. Sans doutes, le Nigeria a besoin de développer immediatement des programmes du depistage cervical pour des femmes hors de l'hopital a un endroit culturellement acceptable. A Idikan, une region a Tinterieure d' Ibadan, on a deja commence une 'etude de depistage cervicale pour la predominance de 1'infection de neoplasie intraepithelial cervical (HPV). Les defis et les experiences rencontres a 1'execution du projet qui pourrait servir comme une connaissance utile aux entreprenant des exercices semblables qui ont besoin de P argent pour le depistage cervical des gens mal renseignes sont mis en valeur. Notre experience au cours de cette etude est importante en tant qu' il a fait sortir les influences vraisemblables de dynamique de la communauté et P organisation sociale dans les décisions de la maladie et les prescriptions pour les personnels medicales de ce groupe particulier. Les programmes de depistage du cancer cervical devraient accommoder les résultats occasionnels par conséquent comme nous avions rencontré, surtout dans les sociétés en voie de développement,~fes programmes exigeraient les dessins sensibles qui devraient adresser les attitudes culturelies, les conflits personnels, les attentes de traitement et un contexte total de soin préventif.

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Introduction

Cervical cancer is a major public health problem worldwide and it remains one of the commonest malignancies in Nigeria [1,2]. In spite of the noticeable decline in incidence and mortality of the disease in the developed countries, these indices remain unchanged in most developing countries [3]. Screening remains the most effective tool for the detection of pre-invasive stages of cervical cancer, giving the opportunity for prompt and effective treatment before the emergence of invasive disease. In societies where cervical cancer screening has achieved its objectives, the standard of education and level of awareness are high, health services are well organized, well-funded and accessible. So far, most of the initiatives at cervical cancer screening in Nigeria have been hospital-based [4]. Even these are underutilized despite the fact that such services are part of family planning programmes, comprehensive health services or offered as opportunistic tests. Undoubtedly the

majority of the women arc not reachcd either because they are unaware, the facilities are limited and inaccessible or they simply choose to avoid such tests [5,6].

In Nigeria, as in most developing countries, the concept of screening for cancer and its pre-emptive treatment is not well developed or organized. The fact that the facilities and logistics for cervical cancer screening are generally located in the hospital setting, a place were one goes when ill, according to local beliefs makes acceptance more difficult. It is obvious that the problems of screening for any disease in such countries arc different from those encountered in the developed countries [5,7]. Preventive health behaviour is society-specific and the identification of enabling factors may help in designing measures that will encourage acceptance and continued use.

That Nigeria urgently needs to set up or develop cervical screening programmes that will reach women outside the hospital setting in a culturally acceptable milieu is not in doubt. A community cervical screening survey for the prevalence of cervical intraepithelial neoplasia and HPV infection was initiated in Idikan, a poor-urban inner core area of Ibadan. The problems and experiences encountered in the execution of the project which could serve as useful knowledge to those undertaking similar exercises, requiring mass mobilization for cancer screening of an uninformed group, are highlighted.

Materials and methods

The study site is located at Idikan, a poor urban, low socio-economic inner core. North west area of the city of Ibadan. Ibadan is located in the South western part of Nigeria in tropical West Africa. The area is divided into 5 local wards with 1821 households. The Department of Preventive and Social Medicine, University of Ibadan, has operated a sponsored primary health clinic in this neighborhood for more than 30 years. The resident population is predominantly Yoruba, with a Muslim: Christian ratio of60:40. Available demographic data of Idikan from locally conducted census indicated a population of approximately 7883. The estimated number of males and females over 15 years are 2468 and 2812 respectively.

The planned aspect of the study was to get to know the community, establish a rapport with the target population, undertake a semi-structured questionnaire interview and perform a cervical smear in consenting women. Entry into the community was through a public health sister and a community mobilizer who were familiar and well known to the people. They introduced the team to the community leader and ciders, to intimate them about the project. Through the mobilizer and the elders, the women were informed in the church, mosque and households to mobilize the women group for initial community meeting with the team. At the gathering with the team, the women were informed about the benefits of cervical screening and that those discovered with disease will be treated.

Subsequent to this, recruitment of women was done on house to house basis by interviewers, who were all women. Meetings were also held with the women group at intervals during the screening period to solicit their opinions and suggestions. Trained community nurses did physical examination of the women and cervical sample collection in the clinic. Patients identified with positive smears were referred to the University College Hospital (UCH), Ibadan, for follow up colposcopy and treatment. Minor ailments were treated on site. From the first day of encounter with the community leaders, a daily record and logbook of our formal and informal interactions were kept as well as the records of daily attendance at the clinic.

Results

The important observations related to the objectives of this communication arc:

Meeting with the community leaders:

This was a vital first step in our getting into the community, working without suspicion, and achieving maximum cooperation from the women. The leaders comprised six males, aged between 63 and 77 years. From the Community Health Sister, we were informed that the leaders were responsible for endorsement of all health activities that involved members of the community at large.

After listening to our expressed intentions, they asked, what could be summarized into 6 questions:

- *Why did you choose to come to this community... and, have you visited, or will you visit other communities?*
- *What will be the benefits and material cost to women who undergo this test?*
- *Is this test painful?*
- *If a problem or disease is detected, do you have a cure or relief for it?*
- *Are you sure that this test will in no way harm the women, their husbands or ajfect their child bearing?*
- *Will the test be extended to men?*

We observed that following this meeting with the male elders of Idikan community no mention was made of our meeting with the older women for them to take a decision for younger ones of their gender in the community.

Meeting with the community:

The entire project team met with the community, approximately 75 people attended, on the afternoon of July 21*, 1998. The first striking observation was that, practically all persons in attendance were females. There were only two other males apart from the committee of elders. There were lots of singing and chatter before the discussion. The women were subsequently informed about our project, safety of the test for the women and emphasizing the value of reproductive health. The women asked a lotofques-

tions about the test and its usefulness. There seemed to be a lot of interest in participating in the project. The women in attendance raised the issue of the sexual behaviour pattern and proposed the inclusion of very young (12-13 year old) sexually active girls.

Without any form of prompting, each of the community leaders who spoke thereafter, expressed support for the project, and enjoined all women to make themselves available for the tests. The presence of a foreign collaborator appeared to underline the importance of the project.

Screening exercise

At the commencement and during the earlier weeks (4-6 weeks) of the project, compliance of the women was very encouraging, with 20- 30 women reporting daily for clinical assessment. Thereafter, the number declined to an average of 10 women attending daily. By the 11'" week, there was a sharp fall in number. At this stage, mobilization effort was intensified. At the interval meetings with the women during this period the following problems were identified:

- Timing of clinic visits coincided with their occupation and means of livelihood. Some of the women were away to the farm settlements.
- Social taboos and rumours about vaginal examination, which was viewed by some as involving the removal of the uterus.
- Difficulty in getting the older women to participate. Their view was that once they had stopped having children or were no longer sexually active, there was no pcrceivcd need to have vaginal examination. The women did not see the need for this screening especially since they are well.
- The negative attitude of the older women discouraged the younger women living in the same household.
- Expected inducement for subjecting themselves for screening
- Refusal of the spouse to allow participation.

Preliminary report of the project.

Of the 2873 expected number of women older than 15years, 1263 responded with a participation rate of 43.96%. Approximately 66.7% of the study population was married, 11.6% were widows and 4.0% were separated from their spouses. 36.2% of the women had no formal education, while 31.8%, 23.7% and 2.7% had primary, secondary or tertiary level of education respectively. While 79.8% of the women had no job, 19.9% had some work experience, 15.7% of those working were mainly involved in petty trading. Only 0.8% of the women have had Pap smear done before while 98.2% had never heard about Pap smear. Less than 25% of the cases with cervical intraepithelial neoplasia grade 3 (CIN 3) and invasive cancer consented to having treatment in spite of advice from the medical team and the agreement of the hospital to subsidize the treatment.

Infact, some of the women temporarily left the community to visit relations elsewhere to escape further appeals. As this report was being prepared, we checked on the clinic records for the six months after the project, and noticed that not one single request for Pap smear was made, despite the fact that the clinic staff were told that such requests should be entertained.

Discussion

In taking a service to the community, the knowledge, attitude and the perceived concept of the service can modify the total acceptability and operationally of such a service. The outcome of such community-based service would then depend less on the negative modifiers of a perceived initial readiness. It has been noted that health services may be underutilized and health instructions ineffective or ignored in traditional and transitional societies where people's ideas and behavioural patterns conflict with modern health information [8]. In order to improve the efficiency of such a service, the initial planning should include specific consideration of the culture, attitude and knowledge of the community. In instituting a cervical cancer screening service in Ibadan, the "standard" approaches operative in the developed countries will have to be adapted to the illness behaviour, social attitude as well as identified motivational factors in our community.

Our experience highlighted the critical role of the community ciders, opinion leaders who essentially play a paternalistic role and exert a permissive effect on health measures. Interestingly, the project team met with six community leaders, all males, even though this was a health issue that affected and was directed at women. The fact that no female was specially invited to specifically ask us about this essentially female condition was striking. It is not clear if this was due to unquestioned deference to the male ciders' revered opinion, or if silence in this setting did not necessarily translate to consent or concurrence. It was our understanding and perception that these male elders endorsed health activities in the community. In retrospect, the elderly women in the community should have been involved at the planning stage. It is likely that they would have had more influence on the women folk.

During the project, it was noticed that the attitude of the older women created a problem and their reluctance to participate influenced the women living in their vicinity. It was observed that we had more non-responders in households where reluctant old ladies lived.

The role of the husband in this community is significant as he also exerts influence on the response of the wife to health issues that affects the woman directly. This probably stems from the male cultural attitude towards their wives and their concept of the issue of ccrvical screening. The men might perceive this as a violation of their women and the fear that contraception might be given to prevent pregnancy or make the women promiscuous. This shows that health education about issues affecting women

must also involve the men for a better understanding and effective utilization of the provided service.

It is difficult to assume that the public endorsement at the community meeting was a common acceptance of the concept of cervical screening which would enhance participation. It is possible that the endorsement of the Pap smear in this context was probably "authoritarian". Men have been described as generally having an "authoritative" or "directive" leadership style than women [9], and this may be cxpectcdly exaggerated in male-dominated societies as the one studied.

As indicated, initial compliance and response were high but not sustained. The decline in response noticed after 2 months, was probably due to rumour mongering, misinformation by some women trying to dissuade participation, d^c to misconception about vaginal examination and taking of cervical smears. This misconception is not unique jtot Idikan, our study site, as similar problem was identified amongst rural black women in South Africa [7]. The Importance of interpersonal exchanges can be either encouraging or discouraging in making personal decisions, such as taking the test or not. It is important therefore that the first few bold clients of a new service must be appropriately educated and informed about the service. It would be useful to institute a feed back system in the early phases of commencement of cervical screening programmes from such a bold group of women in order to ensure proper understanding and implications of the facilities, it fe important not to make any assumption about the understanding of the patients in a setting like ours. Individual perceptions of the aetiology of a disease affect the perception and utilization of suggested or provided curative measures.

It should be noted that the introduction of new ideas may tye met with unpredictable responses and attitudes. The dasual enquiry of elders of Idikan into what the Pap smear "entails could suggest elements of concerns, fear and worry. One author [10] has pointed out that the concept of screening for a disease and its preemptive therapies is strange to people of developing countries. We have seen here, that a purported "good" is suspect, unless it has been tried and tested in other communities. This was the thrust of the question by the elders: why here? What about others? Basic distrust of the reason for the project and the belief that they should be compensated for participating are all indicators of the lack of trust and anxiety of the community about the concept of screening. Exceptionally efforts must be made to reach those women who are past the child-bearing age, as they are a reluctant group as already seen. It should also not be assumed that detected positive cases would subject themselves to follow up and treatment, in spite of the supposed good. This reflects the lack of awareness and ignorance of the disease, the possible prevention by screening and available treatment and its outcome. Education about the disease must be a continuous process throughout the different stages of the programme.

The mobility of the women and their occupation must be taken into consideration when planning a social service. Clinic times and location may have to be tailored accordingly. In this particular group of women who are mostly traders, screening clinics may have to be located in the vicinity of market places for acceptability. The participation rate of approximately 44% is quite low considering the intensity of the mobilization effort involving such a small closed community. The significance of the level of education on the participation rate is difficult to determine but it is likely to be related to the level of awareness about the disease and health issues in general.

Our experience in the course of this study is important as it highlights the probable influences of community dynamics and social organization in illness decisions and prescriptions for health operative in this particular population group. Cervical cancer screening programmes should therefore make provisions to accommodate the occasional outcomes as we had encountered. In addition, screening programmes in developing societies would require sensitive designs that should address the cultural attitudes, personal conflicts, expectations of treatment and overall context of preventive care.

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