

## CLINICAL STUDIES / ETUDE CLINIQUES

**WOMEN'S PERSPECTIVES ON EPILEPSY AND ITS SOCIOCULTURAL IMPACT IN SOUTH WESTERN NIGERIA****LES POINTS DE VUE DES FEMMES SUR L'ÉPILEPSIE ET SON INCIDENCE SOCIO-CULTURELLE AU NIGÉRIA OCCIDENTAL DU SUD**

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**ABSTRACT****Background**

There has been little study of the specific implications of living with epilepsy for women in societies where they already face gender based marginalization.

**Purpose**

Understanding the sociocultural aspects of epilepsy in women will help to improve the management of epilepsy in the community.

**Methods**

A series of six focus groups were held in urban and rural Southwest Nigeria.

**Results**

Epilepsy was commonly attributed to a spiritual attack, witchcraft and other supernatural causes. Denial of the diagnosis of epilepsy was common among women with nocturnal or focal seizures. Majority of women with epilepsy preferred multiple modalities of care in the following order: traditional, spiritual and western. The cost of traditional care was astronomical and most were already impoverished by the time they sought western care. WWE experienced stigma, social exclusion, isolation particularly from paternal relations, in-laws, and community members. Epilepsy related stigma contributed to schooling problems, difficulty in getting married, separation, divorce and problems with childcare and role fulfilment. One unanticipated result of this study was that public announcements made to identify rural study participants created a demand for western health services in rural populations previously unaware that epilepsy could be controlled through western medication.

**Conclusion**

Women with epilepsy face significant and persistent social, economic and cultural barriers. There is the need to educate women, their family and community members to reduce misconceptions and stigma. Community based medical treatment can be improved by taking into consideration the surrounding social, economic and cultural challenges faced by women with epilepsy. The care of epilepsy need to be incorporated into the primary health care system; regular awareness campaigns to be carried out in order to improve knowledge and attitudes and reduce stigma and social exclusion of women with epilepsy. Specific social welfare programmes and educational programme should be established to encourage the full integration of women with epilepsy in the society.

## INTRODUCTION

Epilepsy is a common chronic neurological disorder in Nigeria with a prevalence of 5 to 31 per 1000 population (20, 21). Living with epilepsy in Africa carries with it a higher psychosocial burden compared to many other chronic medical conditions, particularly where effective care and control of the condition is not generally available. This burden is in large measure the result of traditional beliefs that holds that epilepsy is contagious and/or caused by supernatural factors (3, 4, 12, 18, 13, 14, 18, 19). In Nigeria as is the case in other parts of Africa, such negative beliefs contribute to the stigma and isolation experienced by affected persons, with significant social, economic, and medical implications (7, 8, 11, 15, 16).

While all who live with epilepsy face negative attitudes, a small but growing body of research suggests that women with epilepsy may be at particularly risk for poverty, social isolation, marital breakdown and lack of appropriate medical care (5). Allotey's study (2) on the perceptions of persons with epilepsy in rural Cameroon also confirms the negative impact of epilepsy on women's marital lives as all the females in the study were separated and living with their parents. In Nigeria, the patriarchal nature of the society restricts the access of females to economic resources, education and healthcare. Previous studies in Nigeria have demonstrated the psycho-social problems of persons with epilepsy (7, 8, 11, 16) however, there has been no study specifically on the psycho-social impact on women.

This study was undertaken among women with epilepsy in the South-western Nigeria, an area comprised primarily of Yoruba people. The Yoruba population was selected because the Yoruba like other African societies is patriarchal and the culture places many barriers at the doorstep of women. It was anticipated that this cultural attitude toward women would compound the psychosocial issues faced by women with epilepsy.

## METHODS

The study was undertaken in Southwest Nigeria, and involved both urban (Ile-Ife) and rural areas (Owo, and Akoko South -west Local Government area). All the three areas are predominantly inhabited by Yoruba people, which are the dominant and indigenous population of South -west Nigeria. The Yoruba people are a highly patriarchal cultural group with significant gender-related practices, some of which put women at considerable disadvantage compared to men. Ile-Ife, is historically reputed to be the ancestral home of the Yoruba. Ile-Ife is also home to one of Nigeria's foremost University- the Obafemi Awolowo University Teaching hospital, which serves as a referral centre for three states- Osun, Ondo, Ekiti with an estimated population of 9 million.

A series of six focus groups were held, three in urban, three in a rural area and each composed of 8-15 women with epilepsy.

The rural groups were assembled from patients seen in the Federal Medical Centre and Primary Health Care Centres of Akoko South West, Owo. In the rural area, identification of potential participants proved more challenging. Patients with epilepsy seen at the Primary Health Care Centre were invited to participate however, unlike the urban clinics; the number of women with epilepsy seen in the general rural clinics was low prior to the commencement of the study. In order to recruit larger numbers, local community leaders were asked to help identify likely participants and announcements were made in market places, local churches and mosques about the upcoming groups.

All those invited participated. None of the participants in any of the groups knew each other. Verbal and written invitations were issued to potential participants and verbal consent was obtained from each participant. Each focus group was led by two trained staff members fluent in English and Yoruba, and overseen by a co-investigator (Komolafe M.A.) who observed without participating. A checklist of questions was developed for the focus groups discussions by the research team prior to the sessions, with questions based on the literature and previous field experience, covering socio-cultural, economic and health care issues. All sessions were audio taped, transcribed and then translated into English. Analysis was done by the research team using theme content analysis.

Particular attention was given to the perception of epilepsy and its treatment, and the effects on women's employment, education, role fulfilment, and marital relationships. The issue of physical and sexual abuse were also explored.

Ethical permission was granted by the Ethics and Research Committee of the Obafemi Awolowo University Teaching Hospital, Ile-Ife, Nigeria and the Federal Medical Centre, Owo, Nigeria.

## RESULTS

Six main themes emerged from the data: women's understanding of epilepsy and its treatment, family and community attitudes, marital relationships, role fulfilment, socio-economic ramifications of living with epilepsy, and vulnerability to physical and sexual abuse. Each of these is discussed in turn:

### Perception about the nature of Epilepsy:

Sessions began with discussion of how participants understood epilepsy.

Participant's used the following terms to describe seizures, "giri", "warapa" and "ogun oru". Giri means 'shaking' or 'spasm', while 'warapa' means 'wriggling' or 'twisting' in a very stigmatizing term. 'Warapa' implies that the condition is chronic, incurable and connotes a poor prognosis. Ogun-Oru - 'nocturnal warfare' is a term used for nocturnal seizures and is attributed to demonic infiltration of the body and psyche during sleep (1).

Women with nocturnal seizures, focal or secondarily generalized seizures often deny that they have epilepsy -even when receiving treatment for epilepsy. As one woman carefully explained:

*'I don't have epilepsy because I do not foam from the mouth. I know when the attack is going to start, I have an abnormal sensation running up my right arm, my head twists and I fall down- this is not epilepsy (warapa).(24 years, urban)*

Three primary causes of epilepsy were identified: supernatural, contagion and psychical /psychological. The supernatural causes include spiritual attack, a curse, jealousy, or witchcraft generally sent by people envious of academic or financial success. Contagion through direct contact or through food and drinks was another frequently cited source. As one woman stated:

*'My father was a traditional healer treating persons with epilepsy; I think I got it through contact with an affected person.'* (18 years, rural)

Physical conditions were mentioned: birth injury, head injury and lack of immunization. Psychological stresses like 'excessive worries' were also cited. While almost all the rural participants gave supernatural explanations, urban participants more frequently gave physical or psychological explanations.

Women were asked about the type of treatment sought and the sequence in which care was sought from different medical traditions, preferred treatment and costs of alternative treatments (traditional or spiritual). Preferred treatment varied. In general, both rural and urban women reported that they sought traditional treatment or spiritual healing before the western care. Some in the rural focus groups believed that only traditional medicine was effective, reflecting the widespread belief that there are underlying supernatural reason for the seizures. Traditional treatment includes scarification marks made on various parts of the body (forehead or arms or legs) and herbs. Also during a seizure, a spoon was usually inserted into the mouth to prevent clinging of the teeth together.

Spiritual treatment often used in conjunction with traditional treatment, usually involves the woman participating in some religious activities- usually in the church or mosque depending on the religious context and may be resident in the religious building for a period of time as may be prescribed by the 'spiritualist'. Common religious activities include prayer and fasting. Another common practice is the use of holy water-water over which prayers or incantations have been said; the woman may be required to drink the water, bath with it or have it sprinkled over her. Some had tried traditional and spiritual methods before presenting for western care, and some continued both once beginning western care. In the rural groups, many were unaware that western medicine was helpful and those who had tried anticonvulsant drugs had obtained them from local chemists' shops, usually manned by untrained pharmacists. Anticonvulsants in such shops are available only irregularly. Almost all rural women using western treatment said they came to it as a last

resort. Most urban participants (60%) reported coming to western care earlier and believed in combination treatment (western with traditional or spiritual).

Interestingly, the cost of traditional and spiritual care was very high often running between one to two million naira. In the word of one of the participants:

*'It is enough to build a house or buy a vehicle; my parents had taken me to different traditional healers and spiritualists.'* (26 years, rural)

Another woman reported,

*'The time I was taken to a traditional healer, they asked for fifty thousand naira (three hundred and thirty dollars) and a goat.'* (30 years, rural)

Both urban and rural participants reported that many families exhausted their savings on more expensive traditional/spiritual care before presenting to government hospitals for western treatment. Western care in Nigeria is not subsidized; patients have to pay for consultation fees, tests and medications. The average that women report they spend on orthodox care is about 20,000 naira for the initial consultation and investigations and 2,500 to 5,000 naira on follow up visits and drugs. However if the costs of neuroimaging is included it could be up to 100,000 naira. One woman in the urban area reported being sent back to her grandmother in the village for traditional care.

#### **Family Attitudes and Social relationships:**

A variety of attitudes were reported by families and communities. Some women stated that family members were supportive, helping during an attack or assisting with childcare, however many said that they faced rejection and stigmatization.

Many reported that their father and the family of their father were more likely to distance themselves than their mother's family. Thus, matrilineal relations more often described as 'supportive' in contrast to the general negative attitudes of patrilineal relations. In families where the father was unsupportive, siblings were also more likely to be reported as distant or unsupportive. One woman observed:

*'My brothers and sisters called me a witch. They said I am not part of them, that I should pack out and leave my father's house'* (28 years, rural)

Focus group members also reported that women with epilepsy could be called a 'bastard' or 'illegitimate' by siblings. Being thus labelled is of particular concern because a 'bastard' would not have blood ties to the father's side of the family - allowing the patrilineal relatives to further distance themselves.

Due to its stigmatizing status, many women and their families tend to conceal the woman's epileptic status. In some cases, this results in keeping the affected woman away from some family event -so as to prevent the likelihood of the epileptic attack occurring in the open. Many respondents reported that they felt rejected because their families consistently attempted to conceal their existence by not marking important occasions or including them in important public events such as a marriage or naming ceremonies. As one of the participants noted:

*'My father did not do my wedding ceremony. After I delivered, naming ceremony was not done for my baby, they were afraid that I could convulse during the ceremony and bring shame on the family'* (27 years, rural)

Social isolation extended far beyond family units. Women reported difficulties with friendships once their condition became known. As one woman recalled:

*'My close friend got to know (that I had epilepsy) and said 'why have you been hiding this disease from me all this while.' Since then she stopped visiting me'. (20 years, urban)*

Trying to avoid forced disclosure, many women reported restricting their activities; avoiding travelling distances for social events or sleeping in other people's houses.

<http://ajns.paans.org>

### **Economic and Development Consequences:**

Stigma towards those with epilepsy has profound economic consequences as well. For women who have had epilepsy since childhood, education was sometimes significantly curtailed, thereby compromising the development and future economic potential of the individual. Many noted that the fear of stigma makes parents keep a child with epilepsy home from school, rather than send her to school in the fear that an epileptic attack may occur while in school thereby putting the family in disgrace. Girls who are sent to school often leave early, as teachers and pupils react negatively. As one young woman still in school reported:

*'I am afraid of having a seizure in school because my classmates and junior students make fun of me. The teachers also avoid me and no longer send me on errands.'* (18 years, rural)

Lack of education was only one of several barriers inhibiting these women from providing for themselves and their children.

Employment options are also severely curtailed. Women who sell wares reported that once people discover they are epileptic, they will no longer buy from them - presumably because of the widespread belief that women with epilepsy are cursed or that epilepsy is infectious. More prosperous traders travel greater distances to buy and sell wares, but women traders with epilepsy often must restrict their travels, fearing having a seizure far from home.

Fear of infection was of even greater concern for women who work preparing food - (one of the most common ways for poor women to earn a living). One woman who began to have seizures as an adult reported:

*'This illness has ruined me financially. I sell 'fufu'(cooked cassava flower) and nobody wants to buy from me since they got to know I have the condition.'* (20 years, urban)

Women who were learning trades like tailoring and hairdressing reported being dismissed from apprenticeship once their condition was known, as employers fear that customers would no longer patronize a shop harbouring an employee with epilepsy.

In the rural areas, many women stated they were unemployed and living with parents, although some worked on family farms. In both urban and rural areas, many could make little or no financial contribution to their households, further marginalizing them in the eyes of both family and community.

### **Marital prospect and relationships**

Women reported that it was difficult to get husbands as dating relationships often get terminated once their male partners learn of their epilepsy. A woman reported:

*'My fiancé left me 18 months ago because of the seizure and the burn scar on my left upper limb (caused by falling into the fire during a seizure).'* (33 years, urban)

In view of this scenario, many women with epilepsy would fail to disclose their epileptic status to their partners during dating, and such may only come to the fore as a result of seizures occurring after marriage. However, such women may face divorce or separation after their condition became apparent. Pregnancy in the course of courtship may also be rejected by the male partner once the epileptic status of the woman became known to them. Epilepsy also adversely affected relationships with in-laws. Several women, who reported that their husbands knew of their condition before marriage, indicated that problems arose principally from in-laws, especially mother-in-law's. Many women reported that once their mother-in-law learned of their epileptic status, they would be sent away from their marital homes. Divorce and separation were common among women in our focus groups. Most reported their husbands remarried and started new families, and these men may stop or limit financial assistance to them and their children in the process. Many of the women in the focus group discussions who had been divorced reported that they were living with their parents. As one woman reflected of her experience:

*"I had to leave my husband's house for my father's house because of the problem I am facing (epilepsy). My husband threatened to divorce me because I could transmit the problems to the baby". (32 years, urban)*

Another woman reported as follows:

*'My mother -in -law got to know and told my husband 'were you blind when you were marrying? Didn't you know of her condition while you were courting?' I was sent packing the next day'. (22 years, rural)*

Some husbands or relatives did not throw the woman out, but forced them to leave by not providing money for food or living expenses.

Many women reported a downward drift into poverty following such marital breakdown and where children are involved, the economic stresses are still greater. Some women reported they received support from religious organization, but such charity is limited at best. Focus group members also noted that some women with epilepsy, lacking a husband, education, skills and work may turn to transactional sex, particularly if they are turned out of their parental homes. There was wide agreement that: 'If a woman with epilepsy is not properly taken care of she may be promiscuous'; many participants felt that she had few other options.

### **Role Fulfilment**

Many women with epilepsy still report having problems fulfilling their roles as wives and mothers. This was particularly true among rural women who complained of danger or inability to do strenuous work or need to avoid certain household chores like cooking or process cassava over open fires or fetching water from deep wells. Such activities could result in serious injury or death if a woman lost consciousness and fell, sustaining burns or drowning. In the urban areas women are at greater risk of being hit by vehicles or falling from motorbikes- a primary means of transportation. Many said they had sustained physical injuries and burns through such accidents.

Another concern was child bearing and rearing. A number of women believed that epilepsy caused problems with conception, some expressing fears that their irregular menstrual periods were caused by the illness. Some worried about the fact that anticonvulsant drugs may affect fertility. Others feared that seizures occurring during delivery could complicate labour.

One woman reported being sent away after birth of her child as her husband believed she could transmit epilepsy to the baby through contact. For those women with epilepsy who themselves believe that the illness may be infectious, there must be underlying concerns whether they are endangering the life of their children.

A number of women also feared injuring their children during seizures. Risk of injury is high, as children are carried strapped to the back. Some women reported they had assistance with childcare during a seizure:

*'My neighbours help me take care of my baby whenever I have the attack'. (28 years, urban)*

However, many women feared that their child might be injured:

*'I may have a seizure while breastfeeding and injure my child. What kind of mother am I?' (25 years, rural)*

In households where mothers with epilepsy face social isolation and abuse from the husband's relatives, the inability to easily call for help should she feel ill would compound worries about their ability to safely care for their children.

### **Vulnerability to Physical and Sexual Abuse**

One additional concern regularly raised in focus groups is the risk for physical and sexual abuse of women that have epilepsy. Many women reported a higher likelihood of physical abuse if the woman is accused of witchcraft or thought to be possessed by spirits because of her epilepsy. Others reported being beaten as part of 'treatment' in efforts to drive out evil spirits. As one recalled:



*'I know a woman with epilepsy who was beaten with extensive bodily injuries because she was thought to be possessed of an evil spirit.'* (27 years, urban)

It was also widely agreed in focus groups that women with epilepsy could suffer from sexual abuse or rape. While some participants commented that epilepsy would make rape unlikely because of belief in its infectious nature, others felt rape was common. One insisted, 'the stigma of the condition would make men avoid them', but another worried that, if she has an attack in an unfamiliar area she may be raped. Presumably fear of being sexually molested should one have a seizure makes many more wary of venturing far from home - further socially isolating them and limiting their economic options.

Some women also noted that they could be victims of rape for ritual purposes- especially in communities where the false belief exists that having intercourse with a woman with epilepsy can make one wealthy. Therefore, it is not uncommon to find women with disabilities such as epilepsy and mental illness, who have been raped and impregnated by such men.

Another form of abuse was reported from traditional and spiritual healers. It is not unusual for women undergoing treatment to live with such healers during treatments, which sometimes leaves these women open to sexual abuse or pressure to marry. Several reported being pressed into becoming wives or concubines of traditional healers or spiritualists. One recalled:

*'I was taken to a traditional healer for treatment, and the man married me. He did not take care of me and this led to the death of the three children I had for him. I left him.'* (34 years, urban)

## DISCUSSION

The results from our study show that women with epilepsy face stigma and discrimination, resulting difficulties throughout the life cycle, beginning in childhood, where they are often felt to be unwelcome members of the father's family, afforded little or no education, and hidden from the surrounding community. A Yoruba proverb says 'a good child is the father's while a bad child is the mother's.' Presumably, girls with epilepsy are considered 'bad' children. Lack of education was only one of the several barriers inhibiting these women from providing for themselves and their children. In other parts of Africa, it has been observed by previous workers that poor access to education, employment and social exclusion affect both men and women with epilepsy (2, 6, 13, 17, 22), however, gender-based barriers to female education and limited 'appropriate' occupations for women as well as inability to do household chores expected of all adult women worsen the burden of living with epilepsy. This corroborates the findings of Birbeck (5) in Zambia. Hence overall, stigma towards women, problems with schooling and employment has profound economic consequences.

Barriers to women continue into adulthood. Epilepsy is a major impediment to women's ability to marry and have a family. Similar findings were observed by workers in rural Cameroon (2). Njamnshi (18) in a study knowledge, attitudes and practices with respect to epilepsy observed that 48% of secondary school students would object to marriage to persons with epilepsy. Single women with epilepsy reported problems with securing husbands and anticipated rejection by suitors. Siblings were affected and some women experienced negative attitudes and rejection from them and other close relations. The negative impact on siblings has been noted by other researchers (9, 10), but the significant rejection by relations within the patrilineal family structure reported by women in this study has not been noted previously. In Nigeria as in many countries, having a disabled sister or brother lowers the chances of finding good marriage partners for all siblings. In marriage discussions among the Yoruba, it is customary to ask about whether disabilities such as epilepsy are present in the intending spouse's family. It can be a reason for breakdown of marriage negotiations. Many participants also reported that men may promise marriage and even have children with them, but do not follow through, leaving them unmarried with children to support and estranged from their families of origin. Allotey (2), similarly observed that the women in their study were separated and living with their parents.

Should women with epilepsy marry, family relations are also stressed by the illness - often to the breaking point. Many focus group members were separated from husbands because of their seizures. Concerns about the ability to get pregnant were raised consistently. Marriages in South Western Nigeria can breakdown if childless, and women rather than men are usually held responsible for the infertility. It is therefore not surprising that some women said they refused to take anticonvulsants in order to get pregnant. In light of

this, it is important that all women with epilepsy receiving western medications are counselled on the reproductive effects of anticonvulsants and referred, where possible, to the gynaecologists for further management. Should a woman have children, concerns over the possibility that her child could have epilepsy and over her ability to safely care for children were also raised by focus groups. This is similar to the findings of Birbeck in Zambia (5).

Nor do concerns stop there. While access to education, the ability to learn a trade, employment and social exclusion affect both men and women with epilepsy, gender-based barriers to female education and limited 'appropriate' occupations for women, as well as inability to do household chores expected of all adult women, compounds the impact of living with epilepsy.

The cumulative effects of stigma and gender based limitations are devastating, further pushing many women with epilepsy into a downward cycle of poverty. In addition to all other consequences, poverty makes it difficult to procure drugs to treat epilepsy and the vicious cycle is continued.

Finally all focus groups in this study reported sexual abuse and noted that if women with epilepsy are not taken care of by their families, they are at increased risk of being exploited. These women also noted that transactional sex may occur as a result of poverty. In either case, such women are at increased risk of unwanted pregnancies and sexually transmitted infections such as HIV/AIDS. This is comparable to the findings in Zambia (5).

Interestingly, both rural and urban focus groups reported that the psychosocial burden of living with epilepsy is more severe in rural communities, where it rules all aspects of life. This seems to be because rural communities are closely knit, and anything unusual - including an illness such as epilepsy - is quickly discussed by all. In urban areas, people are more anonymous and while family and neighbours may know of a woman's epilepsy, this may not be known in wider circles. It is also possible that urban women with more significant epilepsy might be sent back to rural areas for care by maternal relatives when urban families are too busy to look after them or fear that the woman's epilepsy will hinder a family's ability to get ahead in a competitive urban environment.

These gender-based issues have implications for care seeking behaviours. Women themselves often try to reinterpret or overlook symptoms to avoid being labelled, and first seek traditional and spiritual solutions, contributing to delays in seeking western treatment. It is worthy of note that women came to orthodox care as a last resort after exhausting all their financial resources on traditional care. It is evident that the cost of western care is lower compared to traditional care, however as previously noted by Danesi from Nigeria(8) and Mushi from Tanzania (17), many persons with epilepsy prefer combined care.

Such treatment is expensive and in a society where money for basic education and job training for women is already considered an unnecessary expense by many, girls and women who have drained family resources for their epilepsy treatment and continue to have seizures may find themselves increasingly alienated from limited support systems. Focus groups reported that some women were completely abandoned by relations after care was ineffective.

Interestingly, although it is often assumed that traditional healing is more common in rural rather than urban area, in fact, aggressive advertising by traditional healers and religious organizations on television, radio and on the streets makes people with epilepsy - and many other types of illness - as able and willing to access traditional medicine in urban as in rural areas. The media, continuing to portray epilepsy as a spiritual affliction also encourages continuation of alternative forms of treatment even after receiving anticonvulsant drugs. Danesi and Adetunji (8) observed that more than 90% of people with epilepsy in urban areas received alternative care from one to more than five years prior to seeking western care. This has been reported by others (17, 5) and we also found a strong preference in our urban focus groups for combination therapy (western plus spiritual and/or traditional) after commencement of anticonvulsant drugs.

Nor does western medicine always respond to the perceived needs of the women in our focus groups. One woman aptly observed that the information leaflet accompanying her anticonvulsant drug says that it controls seizures while what she wants is a cure. However, a number of participants also attested to the efficacy of western treatment, and were ready to take anticonvulsants especially if they are highly subsidized or free.



Unintended consequences: Because there were few cases of epilepsy seen in rural health centres, study participants were sought through community announcements. Many in the rural communities were unaware that western medicines for epilepsy existed. The announcements regarding the study therefore prompted a significant increase in the numbers of people with epilepsy coming to the local health centres for care.

## CONCLUSION

This study raises specific cultural issues regarding women and epilepsy among the Yoruba's of south west Nigeria. It is evident from our findings that not only is improved access to treatment and care needed, but also concurrent efforts to address the gender-based stigma, and prejudice that such women face in both urban and rural communities. The government, working with health care providers would be well advised to undertake interventional public educational outreach programmes for women with epilepsy, their families, caregivers and general public. The approach should be community based and integrated into the primary health care system of the country. Such programmes should address the perceptions, misconceptions, cultural attitudes and practices that affect the female gender.

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