Social aspects of dementia in Central Africa (EDAC Survey)

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SOCIAL ASPECTS OF DEMENTIA IN CENTRAL AFRICA (EDAC SURVEY)

LES ASPECTS SOCIAUX DE LA DEMENCE EN AFRIQUE CENTRALE (ETUDE EDAC)

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ABSTRACT

Introduction
According to the World Health Organization, dementia poses a public health problem in sub-Saharan Africa because of the growing number of elderly. But the perception of this condition is poorly documented in low-income countries.

Objectives
To Identify and analyze the perceptions of dementia in different population groups more or less concerned. Method

A Cross sectional study was conducted following a general population survey on dementia between October and December 2008 in Bangui and February-March 2009 in Brazzaville. Five groups of subjects were involved. The stigmatization of people with dementia was assessed using scale consisting of 15 questions. The Stat View 5.0 and SAS 9.1.3 software were used for data analysis.

Results

The subjects of the groups interviewed were dominated by women with the exception of nursing staff. There was no equivalent to the biomedical concept of dementia in the local languages of the two countries in which the study was conducted. The problems of inability to work (73.3 to 82.7%) and reduction in family income (55.7 and 79.0%) were reported by subjects with mild cognitive impairment. The emotional impact was dominated by concerns about the progression of cognitive problems (52.5 to 76.8%), sadness and anxiety (50.8 to 79.4%).

Conclusion

In urban zones in Central Africa, we find that perceptions of dementia include traditional and magical-religious aspects, even among health care workers who supposed best placed to provide tailored information.

Keywords: dementia, social representations, stigma and discrimination, Central Africa

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RESUME

Introduction

Selon l'organisation mondiale de la santé, la démence posera un problème de santé publique en Afrique subsaharienne, en raison du nombre croissant de personnes âgées. Mais, la perception de cette affection est insuffisamment documentée dans les pays à faible revenu.

Objectif

Identifier et analyser les perceptions de la démence chez différents groupes de population plus ou moins concernés.

Méthode

Etude transversale menée à la suite d'une enquête en population générale sur les démences entre octobre et décembre 2008 à Bangui et février-mars 2009 à Brazzaville. Cinq groupes de sujets ont été concernés. La stigmatisation des personnes atteintes de démence a été évaluée par une échelle composée de 15 questions. Les logiciels Stat View 5.0 et 9.1.3 SAS ont été utilisés pour l'analyse des données.

Résultats:

Les groupes des sujets interviewés était dominés par les femmes à l'exception du personnel soignant. Il n'y avait pas de terme équivalent à la notion biomédicale de démence dans les langues locales des deux pays. Les problèmes d'incapacité de travailler (73,3 à 82,7%) et de réduction du revenu familial (55,7 et 79,0%) ont été rapportés par les sujets atteints de déficit cognitif léger. L'impact émotionnel était dominé par les inquiétudes au sujet de la progression des problèmes cognitifs (52,5 à 76,8%), la tristesse et l'anxiété (50,8 à 79,4%).

Conclusion _ Dans les zones urbaines en Afrique centrale, nous constatons que les perceptions de la démence comprennent des aspects traditionnels et magico-religieux, même chez le personnel soignant censé être le mieux placé pour fournir des informations adaptées.

INTRODUCTION

Dementia is among the most important public health problems, due to the increasing number of elderly people in the world [16, 17, 19]. But the perception people have of it has not been studied in some areas, whereas this could bring out how dementia is a social and personal burden, especially with the stigma possibly related to. In developed countries, the prevailing model of comprehension of dementia is biomedical. Some authors criticize this tendency of modern medicine to "expand into almost all aspects of human existence", particularly in the aging [8]. It is different in low-income countries, where the prevalence of dementia is generally lower than in high-income countries [11, 13]. Some studies take account of socio-cultural and socioeconomic situations of patients and of their perception of the problem which affects them. This highlights how culture deals with dementia [3, 6].

OBJECTIVES

The objective of this study was to identify and analyze perceptions of dementia in various population groups, and consider the significance of the social representations.

METHOD

Setting and sampling

This survey was part of a larger study of dementia in Central Africa (Epidemiology of Dementia in Central Africa, EDAC) conducted between October and mid-December 2008 in Bangui and in February-March 2009 in Brazzaville. In both places, a two stage prevalence survey was carried out among people aged 65 years and over. Stage 1 was cognitive screening by local doctors trained in the use of neuropsychological tests, and stage 2 was confirmation of dementia by neurologists [9]. Our study took place after the confirmation stage diagnosis of dementia was used to classify respondents into two groups: demented and those with mild cognitive impairment.

Semi-structured interviews were conducted in the homes of people with suspected dementia by local investigators trained to the use of the Explanatory Model Interview Catalogue (EMIC) [23]. This interview guide is notable for its trans-cultural validity and adaptability. Initially constructed in a developing country, India, it was subsequently adapted for use in North America, Western Europe, Africa and East Asia. Both quantitative and qualitative data was collected. Grids covering preset items take in consideration representational models in the perception of dementia. Thus, patterns of distress (PD), perceived causes (PC) and help-seeking (HS) were checked by the investigator when the person interviewed spontaneously mentions in his or her account one of the items on the grid. Then, the interviewer inquires about the items not spontaneously mentioned to determine whether they are seen as representations of the problem. Subsequently, the person interviewed chooses the item that he or she perceives as the most important.

The EMIC used was based on a version in English concerning tuberculosis. That questionnaire included 110 questions divided into six parts. We selected questions

according to their adaptability to the area of interest, and their suitability for the context and the study population. Forty-five questions divided into five sections were selected and translated into French. These 5 sections were: sociodemographic characteristics, familiarity with dementia patterns of distress (PD), perceived causes of dementia (PC), an evaluation scale of stigma, and help-seeking attitudes (HS). A brief vignette of dementia was used to invite people to talk about this topic. A multidisciplinary working group translated the EMIC into local languages (Sango in Bangui, Kituba and Lingala in Brazzaville). To assess perceived stigma, a score was calculated by the sum of the answers to 15 questions, each question rating from zero to three points each. The internal validity of the perceived stigma scale was calculated as 0.7 using Cronbach's alpha.

The sample of people tested was composed of five groups according to their degree of experience of dementia : elderly people with confirmed diagnosis of dementia (DPs), people close to a person with dementia (DP-Rs), elderly people with cognitive impairment without dementia (CIEPs) (they had cognitive scores < 25.5/30 at the CSI-D and < 10/10 at the FWT like the DPs, but dementia was not confirmed by the neurologist), and people close to the latter group (cognitive impaired without dementia group). The last group was hospital caregivers (HWs) (physicians, GP, specialists, nurses, social workers etc.) who were asked to participate where they worked: the CNHU (University Hospital) and community hospital in Bangui, and Brazzaville University Hospital. All participants consented orally or in writing after receiving information about the purpose of the research.

Analysis of data

Digital data were entered in Excel, and text in Word. Stat View 5.0 and SAS 9.1.3 (SAS Institute, Cary, USA; see http://www.sas.com/), were used to analyze quantitative data. Text was studied using the lexical software MaxQDA 10 (VERBI software, Berlin, Germany; see http://www.maxqda.com/). Quantitative variables were presented as mean ± standard deviation or expressed as frequencies and percentages. Categorical variables were compared between groups of subjects using Chi square tests or Fisher exact tests. Distributions of quantitative variables were compared with Student's t-test when the distribution followed a normal distribution (verified with the Shapiro-Wilk test). If the variable did not follow a normal distribution, the non-parametric unpaired Wilcoxon test was used. Correlations were determined using the linear correlation coefficient (r). A significance level of 0.05 was adopted for all statistical analyses.

RESULTS

Characteristics of the sample

The groups were predominantly female with the exception of HWs (Table I). The mean age of DPs was higher than that of the CIEPs. The ages of the groups of relatives were similar. Almost all respondents described themselves as Christian. Most elderly people were widowed, with higher proportions among DPs than CIEPs. Older people often had little formal education. In contrast, 86.0% of related people were educated. Apart from the HWs and CIEP-Rs, most respondents reported having a rather unstable and irregular income. DPs and DP-Rs were more likely than their counterparts to be in that situation.

Recognition of dementia

There was no term equivalent to the biomedical concept of dementia in the Sango (Bangui), or Lingala or Kituba (Brazzaville) local languages. The biomedical concept of dementia was unknown other than among health professionals. However, the signs and consequences of the disease were well-recognized by the great majority (88.0% of individuals (all categories) in Bangui, 57.5% in Brazzaville). A man reported for example: "I do not recognize dementia as a disease but as the signs of ageing. I live with people with dementia in my family. Dementia makes life difficult and does not allow them to move or to carry on daily activities" (DP-R, 37, Bangui).

Models of understanding of dementia

PD, PC, and HS were expressed by frequencies of reported items in spontaneous answers and after probes. We considered the total frequency of both (spontaneous answers and probes), as well as the percentages of models of distress and perceived causes chosen as the most important.

Patterns of distress (PD): the symptoms

The majority of individuals in every group, whether in Bangui or Brazzaville, most commonly raised symptoms such as forgetfulness (77.8 to 98.4%), difficulties in retaining new information (55.6 to 84.1%) and problems with mobility (51.3 to 62.2%). Other symptoms such as diminished ability to recognize people and objects, and diminished ability to perform activities of daily living (ADLs) were also raised in Bangui (53.6 to 38.8%). In Brazzaville, problems with verbal fluency, changes in behavior or personality, and disorientation in space and time (75.4 to 58.2%) were remarked upon.

Some specificities depending on the different groups of people can be also highlighted. Elderly people generally raised less or similar rates of symptoms, apart from problems with mobility (elderly, 61.7% versus 52.0% of relatives). Concerning the relatives, the DP-Rs often reported personality changes (45.9%) and verbal fluency troubles (62.3%), whereas higher rates were obtained by the CIEP-Rs to the "other symptoms".

Patterns of distress (PD): the problems

Respondents focused on the socioeconomic and psychological problems that result from dementia. Inability to work and produce income was raised (73.3 to 82.7%), as was reduction in family income (55.7 to 79.0%). Both were particularly reported by the CIEPs (82.7% and 79.0%). The emotional impact of those issues was recognized, in particular by the elderly: worries about the progression of cognitive problems affected 52.5 to 76.8%, sadness and anxiety, 50.8 to 79.4%. A woman reported: "this problem has many consequences in the life of a person, so many that it isn't possible to mention all of them: pain in the back, legs, eye troubles, malfunction of the nerves, non-recognition of people, loss of everyday gesture. I cannot walk to the fields, my unique source of income. I am very concerned about the loss of income this generates for me and my family" (CIEP, 69, Bangui).

Perceived causes (PC)

According to the majority of interviewees, the symptoms mentioned were explained by the effects of ageing (54.6 to 77.1%) and the mental or emotional stress experienced by those affected (51.1 to 90.5%). These two causes were more often reported by the relatives (76.6% and 65.6%). A man said: "My grandmother who lives

here has behavior like that. But I realized it was old age that leads her to do this. Now, she doesn't move outside the family's dwelling. She no longer works. I think old age, first, causes this condition" (DP-R, 30, Bangui).

God or destiny was also a very common explanation according to the CIEPs (24.3%) and their relatives (10.0%), as part of a broad explanation of life and its development in general. God was thought to decide for everything in everyone's life (life, death, good health, illness, recovery). For example, a woman said: "I think that only God can decide. God has the power to give diseases. But some diseases can also be caused by witchcraft" (CIEP, 82, Brazzaville). Indeed, magico-religious explanations (witchcraft), very common in Brazzaville (20.5% of spontaneous responses and 50.2% of probes), were often reported by the elderly, and in particular the CIEPs (44.4%).

The physical demands of work were more often cited as a perceived cause by the elderly (64.8%), particularly in Bangui (62.0%). Other causes such as untreated previous disease, bodily injury (accident, surgery) as well as alcohol, cigarettes, drugs and socioeconomic problems such as poverty were also frequently reported after probing in Brazzaville.

The HWs raised very much more causes in comparison to the other groups, essentially due to the probes. This also concerned magico-religious explanations like witchcraft (66.7%), devils (61.9%), and punishment by the ancestors (49.2%). A man explained: "In Africa, the punishment by the ancestors is possible, yes. We don't know if it's true, but people might say it is the cause of dementia. The devil, if the person went to see the black magic or occult houses can also cause dementia" (HW, 37, Brazzaville).Only some rates were lower than the elderly's, but similar to the relatives', like physical exertion or work (47.6%), and God or destiny (4.9%).

Social tolerance of people with dementia

Mean scores for perceived stigma were calculated on a 45-point rating scale. The group with the lowest score was the DPs (12.9 ± 6.6), in contrast to their relatives, whose score reached 14.3 ± 8.0. The score among HWs was higher, at 15.9 ± 5.4, and significantly different from that of all groups of relatives combined (13.5 ± 7.2; p = 0.014).

The narrative accounts provided by respondents indicate that intolerance related to magico-religious attitudes toward deviant behaviour shown by people with dementia. According to one 29-year-old woman (CIEP-R, Bangui): "A person with dementia is not respected... those who are demented are regarded as witches because of their behaviour". However, such perceptions were not limited to deviance, as the elderly in general were seen as typified by certain characteristics and magico-religious beliefs: "I think we do not respect them because of their age, old persons are part of another world," said a 46-year-old woman (CIEP-R, Brazzaville).

Social intolerance of dementia also resulted from the idea that older people become "useless" to society. "People do not respect them because they are unproductive," said an 81-year-old woman (CIEP, Bangui).

Nevertheless, there are limits to intolerance. Social support is important because it is based on traditional values, whether religious or simply deeply rooted in human society: the family ties between parents and children, marriage bonds, helping others, respect for older people who have given birth and brought up children, served

their country and so on.

Preferred approaches to help-seeking

These models of understanding of dementia revealed preferential choices of help sources by those affected by dementia. The percentages of spontaneous responses and probes indicated that modern medicine was predominately preferred (public hospital, 86.7 to 93.9%; GP, 56.8 to 79.4%; specialist, 56.4 to 100.0%). This was particularly true in Brazzaville, where the percentages of probes exceeded 70.0% for several resources offered by modern medicine (medical staff, pharmacist, health centre, private hospital, psychologist, social worker). However, religion was frequently cited as the main recourse by the CIEPs and their relatives (27.5 and 21.2%; versus 7 and 6.3% of DPs and DP-Rs). Personal or family care, that is to say looking after oneself with support and assistance from family members (39.0 to 52.4%) was an appreciably common choice. In Bangui, the use of traditional healing was also often recommended (37.0%).

The HWs cited many more help sources, essentially due to the probes. Traditional medicine (herbal medicine, 57.2%; traditional healer, 47.6%) and magico-religious help (magically revealed herbal medicine, 31.8%; medium, 30.2%; magico-religious faith leader, 30.1%) were also concerned. A woman said: "The magico-religious healer can give you answers. But in the long run, you'll go back to the Doctor because there may be contraindications. The medium can help yes, not the fetish but someone who prays in the right direction" (HW, 57, Brazzaville).

DISCUSSION

Our results showed that, in Central Africa, despite the lack of a term for dementia, signs of the disease were recognized in the population and generally explained by the damaging effects of ageing. This confirmed what has already been shown, for example among the Yoruba who, as reported by Ineichen [13], recognized elements of senility ("back to childhood", etc.) but did not assign them a specific term [7]. A large proportion of elderly respondents identified themselves as affected by the problems described by the vignette, even if they associated other conditions with this notion of "dementia". Sometimes, denial of problems was identifiable (a possible sign of anosognosia in people with dementia), but it may have been a strategy of self-preservation rather than true denial [4].

Consequences of dementia that were the most reported and highlighted by the survey population were emotional and socioeconomic impact of health problems related to age. Sadness, anxiety and concerns of the elderly were subject of significant attention. So, the "socio-emotional concerns", unlike evidence from Hulko [13], were not inferior to "instrumental concerns", in this low-income population.

Apart from ageing, life events, and the effects on the body of hard work, were frequently implicated in the explanations of dementia. Nevertheless, anxiety or tension caused by the unusual behaviour of people with dementia also encouraged beliefs in witchcraft and curses. Rasmussen [21] made this observation among the Tuareg of Niger, who suspected people with dementia of having failed in their duty to say their daily prayers.

Spirituality played an important role in individual narrative accounts. For many people, the elderly in particular, "God knows everything as He created the world, and therefore has the power to decide the fate of each of us, sickness or health".

According to the point of view of the Bantu people, the Koongo for example, "man is defined by the human body, nitu, blood, mèenga, breath or vital principle, tsigumùnu, and soul, tsiluunzi". This implies that the body is intrinsically linked to its social environment. Death is conceived "as a transition, a metamorphosis rather than the end of life. It does not cause a rupture but opens a new way to exist" [22]. The social network, in such a cultural context, is very structured and relies on these strong values added to the family and community ones. It strengthened the supportive attitudes often perceived as beneficial to health, and counteracted the tendency to stigmatize. Because, stigma, this old "universal phenomenon", which implicates a variety of individual, relational, community and societal risk factors, according to the WHO [18], clearly still exists, as indicated by the results.

Even so, and contrary to what is often stated, here the narrative accounts do not confirm the notion that "traditional healers ... often act as first recourse" [6]. And, even if "access to geriatric care in Africa is very limited" [14], modern medicine remained the first choice of help. But, help resources were not mutually exclusive and seemed to be rather complementary to each other. Indeed, one of the characteristics of modern medicine is, according to Cohen [5], "isolation of the body and a denial of subjectivity". That's why biomedical explanations can be difficult to integrate when great emphasis is placed on the spiritual dimension. Attitudes are changing, but perceptions are difficult to change at their core [15]. It is therefore essential to consider the representational universe of people affected by dementia before trying to introduce new representations that define a purely biomedical condition.

Representations are influenced by age, education level and knowledge system, as well as cultural environment and closeness with the disease. Thus, in Bangui and Brazzaville, some representations were common whereas others were more specific. In Bangui, traditional representations tended to be more present. In Brazzaville, magico-religious explanations as well as biomedical representations were used. Despite the same global context (Central Africa), historical and cultural background of the city or country influences people's minds. Some representations were also more specifically found according to the groups. Elderly people had a more traditional view (hard work, God, witchcraft in cause) than their relatives, whereas these expressed opinions more influenced by biomedicine (stress and ageing as given causes). Closeness to the disease also seemed to influence the representations: DPs reported more symptoms, more sadness and anxiety and had more difficulties to explain the trouble. CIEPs were preoccupied by the inability to work and the decrease of family income. For them, magico-religious explanations were more often given as causes. So, the experience of the disease by the person affected or relatives seemed to decrease the imaginary representations. Finally, HWs generally reported many more symptoms, problems, perceived causes and help than the other groups. Only some of the perceived causes (physical exertion or work, God or destiny) and help (religious leader or religion) were not as frequently reported. Several other traditional and magico-religious causes and help were present. Anything that might help was worth taking. Thus, representations were not really specifically used or reserved to certain groups of population. This also concerned stigma. Some studies showed that doctors and medical students endorsed stigmatizing attitudes towards mental illnesses and were especially prone to see patients as blameworthy [7, 15]. Adewuya and Oguntade [1] reported, for example, that in Western Nigeria medical Doctors perceived the mentally ill persons as dangerous and were rather pessimistic concerning the prognosis of the illness. This was similar to the social representations non-professionals have, like it was shown in other countries in sub-Saharan Africa for example [2].

This study brought results even if some methodological limitations have to be taken

into account. In particular the translation into local languages of the questions constituted a limitation. The subsequent translation of the answers into French, that is to say their retranscription and interpretation, represented also a significant limitation. Being aware of these limitations, we paid particular attention to the entire process of preparing the interviews and analyzing the data.

CONCLUSION

Biomedical conceptions of old age described in developed countries as well as the biological mechanisms have limits. That is why in addition to the rapid social change in Africa, the biomedical approaches risk to cause harm in a context where spirituality plays such an important role. Local caregivers are, from this perspective, the key elements in creating a health system that reconciles these multidimensional aspects.

Declaration of interest

The authors declare that they have no conflicts of interest related to this article.

Tableau I : Répartition des sujets inclus dans l'étude, Bangui et Brazzaville, 2008-2009.

Group of responders	Male	Female	Average age (years)
Confirmed dementia	10 (22.2%)	35 (77.8%)	73.9 ±7.1
Relatives with dementia	15 (24.6%)	46 (75.4%)	48.2 ±6.8
Mild cognitive impaired	48 (25.9%)	137 (74.1%)	71.9 ±6.5
Close mild cognitive impaired	59 (30.3%)	136 (69.7%)	53.5 ±8.2
Health care workers	55 (87.3%)	8 (12.7%)	38.7 ±3.8

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