

Research Article

Stigmatisation and Discrimination Surrounding Diabetes Care in an African Context: Examples from Cameroon

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Citation: Awah P (2017) Stigmatisation and Discrimination Surrounding Diabetes Care in an African Context: Examples from Cameroon. J Diabetes Treat: JDBT-131. DOI: 10.29011/ 2574-7568. 000031

Received Date: 27 October, 2017; **Accepted Date:** 17 November, 2017; **Published Date:** 24 November, 2017

Abstract

This paper illustrates how stigmatisation and discrimination are orchestrated against people with diabetes in an African context. Case studies from Cameroon are used as an illustration to engage in a dialogue with other published works about discrimination relating to people with diabetes. The data for this study was collected from June 2001 to June 2003 using participant observation in the rural health district of Bafut and the urban health district of Biyem-Assi in Yaounde, the capital city of Cameroon. Case study analyses were performed entailing the identification and the interpretation of themes emerging from and grounded in the selected cases. Analyses were done through grounded theory. Although people with diabetes were open and assertive about their condition, they suffered stigmatisation and discrimination orchestrated by their families, their peers, employers, healthcare providers and the state. Stigmatisation and discrimination were expressed in the form of job insecurity, conjugal rejections, nutritional prohibitions and restrictions, limited clinical care and socialisation and limited state commitment for the course of diabetes prevention and care when compared with communicable diseases. These dilemmas are, therefore, not only restricted to people living with HIV/AIDS and other infectious diseases but also involves people with diabetes and possibly other chronic diseases. Involving these stakeholders in culturally engaging, and culturally inclusive interventions may eliminate stigmatisation and discrimination and may help in charting a culturally compelling pathway for better health interventions to improve the quality of life for people with diabetes.

Keywords: Diabetes Care; Discrimination; Ethnography; Quality of Life; Right to Health; Stigmatisation

Introduction

By the year 2000, when the world leaders identified and defined the 8 global development goals and called them Millennium Development Goals (Goals), the world powers had not yet considered diabetes and diabetes risk factors as a threat to Global Health so kept them out of the Global Health context and agenda. The World Health Organisation, the International Diabetes Federation and the World Diabetes Foundation embarked on a programme entitled “Diabetes Action Now” whose main aim was to create awareness about diabetes and to make diabetes care available at grassroots. [1,2] It was a way of producing robust evidence that could qualify diabetes for global health action. But

these efforts encountered some inherent problems, some of which were related to the stigmatisation and eventual discrimination of people with diabetes. The scientific world has been informed about the stigma and discrimination that goes with infectious diseases, especially with HIV/AIDS and unsafe abortions [3-6] and made to understand that stigmatisation and discrimination are not found with non-communicable diseases like diabetes and hypertension [3].

Within fifteen years scientist and researchers produced robust evidence that projected diabetes and diabetes risk factors as main public health threats to global development. Seventeen Sustainable Development Goals (SDG) with 117 targets were defined and a UN Resolution taken and signed by 188 nations. Diabetes and diabetes risk factors were finally introduced in the global health agenda of SDG 3. Stigma is a degrading and debasing attitude of the society that discredits a person or a group because of an attribute (such as

an illness, deformity, colour, nationality, religion). Much evidence about the issue of stigma has been highlighted and documented in Africa [3]. It is very important and has been used in stepping up the battle against HIV/AIDS in Africa. These efforts are made to reduce it from affecting patient attendance at healthcare centres for obtaining Antiretroviral (ARV) medications and regular medical check-ups. Stigmatization creates an unnecessary culture of secrecy and silence based on ignorance and fear of victimization, hence discrimination. Very little evidence exists demonstrating that people with diabetes face similar cases of stigmatisation and discrimination. Instead, studies have concluded that the discrimination faced by people with HIV/AIDS does not exist in people with diabetes [3,4].

The coping behaviour of people affected by diabetes result in internalized stigma and externalised discrimination. Social stigma is extreme disapproval of (or discontent with) a person or group based on socially and culturally ascribed attributes. These stigmas put a person's social and cultural identity in threatening situations, like low self-esteem. The concept of stigma has undergone important shifts in definition and characterization since its initial articulation by Erving Goffman in the 1960s. The study of stigma has focused too heavily on psychological approaches and has neglected to sufficiently incorporate understandings of stigma and stigmatized individuals as embedded in local moral contexts. What exactly is encompassed by the conceptual umbrella of stigma is far more than a compelling theoretical question, since definitions of stigma directly inform efforts to empirically research and combat stigma. Stigma is generally viewed as a process based on the social and cultural construction of identity. Persons who become associated with a stigmatized condition thus pass from a "normal" to a "discredited" or "discreditable" social status. [4,5] It is of interest to understand how social life and relationships are changed by stigma. Stigma decays the ability to hold on to what matters most to ordinary people in a local world, such as wealth, relationships, and life chances. The stigmatized and those who stigmatize are interconnected through local social networks. Although stigma may share features across contexts, it uniquely affects lives in local contexts like African versus the Western societies. Understanding the unique social and cultural processes that create stigma in the lived worlds of the stigmatized should be the first focus of any efforts to combat stigma. Measuring what matters most is facilitated by ethnographic methods like the ones used in this study. The local value systems can be explored in far greater depth than what is possible through standard survey instruments.

Discrimination is usually a resultant of stigmatisation. Discrimination means treating a person unfairly because of who they are or because they possess certain characteristics [4]. When you are treated differently from other people because of whom you are or because you possess certain characteristics, you may have been discriminated against. Discrimination exists in the form of

direct and indirect discrimination, discrimination by association, harassment and victimisation. Discrimination is contextual as with the case of health care.

Discrimination in health care is widespread across the world and takes many forms [5]. It violates the most fundamental human rights and affects both users of health services and health workers, based on issues including ethnicity, sexual orientation, harmful gender stereotypes, asylum and migration status, criminal record, and other prejudices and practices [7]. It is held that discrimination does not occur in a vacuum. Health workers and their own rights are at the centre of this agenda - with labour rights, working conditions and gender inequalities inextricably tied to addressing discrimination in health care settings and a health work force that is largely female. A lot of the discourse about discrimination has a single narrative orientation by which health workers are perpetrators of discrimination. [3-6] Only evidence grounded on anthropological research can provide counter and additional evidence. This evidence may enable the recognition of the importance of supporting health workers not only to fulfil their roles and responsibilities, but also to claim their rights. Discrimination runs counter to global commitments to reach universal health coverage and the Sustainable Development Goals. It undermines investment in health systems, deters people from accessing or seeking health services, divides, disempowers, and deprives people of their basic dignity. Discrimination also affects the social determinants of health. For many people, their interaction with the health system is their only connection to a state institution, directly shaping their very experience of citizenship and all too often, serving to reinforce their exclusion from society.

In other fields, cases of stigmatisation and discrimination have been reported, having to do with transmission patterns of diseases and access to care and support [8]. But with diabetes, particularly in Africa this stigmatisation and discrimination takes a different form and needs being discussed and documented. This paper aims to highlight these issues and provide a rationale for appropriate measures targeting the eradication of stigmatisation and discrimination in the care for diabetes in Africa, given that diabetes now has a more global focus and it is in the global health agenda.

There is inadequate and difficulty in affording care, treatment and support. The role of national and international advocates is critical in achieving this. But faced with the components of stigmatisation and discrimination, more difficult days lie ahead in the strife to obtain an enabling environment for diabetes care. Therefore, the issue of continued equitable access to diabetes care is important and needs to be handled carefully and timely. But except this is brought to the surface, as is the case of this paper, it will lie unknown, like mines in a battlefield.

African countries have been criticised for having some of the worse human rights records [9]. This includes the right to health. Reports of cases of stigmatisation and discrimination have

been more focussed on HIV/AIDS, victims of sexual violence and abortion and people with neglected tropical diseases. But such reports on the right to health need particular attention. Stigmatisation and discrimination exposes people to, not only the risk factors of diabetes, the development of diabetes itself but eventually to complications and death. This may extend to many stakeholders requiring identification. Most African countries including Cameroon have ratified many of the International Conventions and International Human Rights Instruments Standards about the right to health. But these seem to be compromised by different actors and appear like merely paying lip service to the organisations that set them forth. Their ratification may be a means to lobby and obtain whatever windfall gains that may be attached to them, given that they may be a prerequisite for aid from international donors and loans from international financial institutions. It is expected that the laws should protect the rights of citizens to health. But these seem to be compromised by the different actors in the field.

With the upsurge of diabetes to an epidemic proportion in many African countries [10-12], the situation is becoming serious and needs to be addressed [13]. Labour laws prohibit employers from dismissing workers for ill-health purposes. International Instruments Standards stipulate that people have the right to health and need not be discriminated upon. [14,15] The law in Cameroon, like many African countries is not clear on issues relating to ill-health and employer-employee relationship on the right to health. For that reason, the states, employers and health care providers act according to their whims and caprices. However, this gap remains and needs to be understood and redressed in Africa. The daily interaction of people with diabetes and the stigmatisation and discrimination that they go through needs proper understanding for strategic health planning and legislation to enable the SDG 3 target for global health goal for noncommunicable diseases to be attained and sustained. A few studies [3,6] have browsed through this aspect of stigmatisation and discrimination without pointing to them as a real problem in diabetes and diabetes risk factors. The aim of this paper is to illustrate how stigmatisation and discrimination is represented when people are affected with diabetes in order to point out some areas of ethical dilemmas and their implications to public health. We do not intend to do a legal or human right analysis, but illustrate that there are issues affecting access to health care surrounding diabetes care too, especially stigmatisation and discriminations, which are often overlooked.

Material and Methods

Design and Setting

Data for this paper are part of ethnography obtained from two years of extended ethnographic fieldwork carried out in urban and rural Cameroon from June 2001 to June 2003. Bafut and Yaounde were the two fieldwork sites. [16,17]

Sampling and Data Collection Procedures

The sampling and data collection process in the clinic sites was with different research participants. The first contact in the clinic was with diabetes clinic authorities to obtain their permission to recruit patients and use their clinics as observation sites. The participation of health care providers and the observation of patients in consultations and in health education sessions were also sought. Consent of patients was first sought and since observation had to go beyond the clinics to the families, family members' consent was sought through the patients, then in an encounter with adult members of the family and heads of households. Patients whose families accepted participation in the fieldwork were included as part of the study and notification about the duration of the family visits and the nature of the research were made. Wherever possible, a consent form was used, and the purpose of the study explained before conducting an observation and interview. The participant(s), if literate, signed the consent form(s) and if illiterate gave a verbal consent. This multistage approach (Awah 2016 -16) to ethical and administrative clearance and informed consent was to ensure that community and individual opinions favoured the study.

Data Collection Procedures and Analysis

I lived and interacted with the patients, the families, health care providers, state actors and members of the community, for two years, doing participant observation. Participant observation entailed using a wide range of research data collection techniques and tools: observation, interviews, biographies, case studies, life histories, case histories and conversations. It meant being there and living the situations [18]. This approach provided the opportunity to share in the activities of the patients, during which data was collected on biographies and as life and case studies built up. These case studies are a combination of biographies and the social interactions. Observations, interviews, conversations social interactions and active and passive interactions were the main techniques used to build up the ethnography that has been moulded into case studies. This paper uses pseudonyms of research participants and has eliminated markers that could lead to their identification. The paper therefore is part of this ethnography, aiming at contributing to the international debate on the reduction of stigmatization and discrimination in the public health domain as a measure of improving the quality of care for diabetes. I have made ethnographic insights into the case studies to reveal the meanings of certain actions which may seem to be part of normal life, but which impact on the quality of life of people with diabetes. I have, conducted a content and thematic analysis of the cases to tease out meanings from some of the case studies that were developed during fieldwork.

Ethical and Administrative Clearance and Informed Consent

As peculiar with African settings, the informed consent process went through a multistage process. Ethical and administrative clearances were obtained from the National Ethical Committee of Cameroon and the Ministry of Scientific and Technical Research respectively. The Ministry of Scientific and Technical Research is the government authority that authorizes scientific and technical research in Cameroon. These documents were used to further obtain authorization and administrative clearance from the divisional officers, district medical officers and, in the Bafut case, of the traditional ruler, in order to get the local authorization to conduct fieldwork.

Results

Socio-Demographic Characteristics of People with Diabetes

Two hundred patients made up the pool of patients in the sample diabetes clinics. These patients were both male and female and literate and illiterate. Twenty-five percent of the patients were rural dwellers and 75% were urban. Though over fifty patients were closely followed, six with the most revealing evidence are used as representative of patients in the study.

The results are presented in the form of summary cases studies as they unfolded during fieldwork. Five of such cases are presented according to the groups of actors that are involved in orchestrating and sustaining stigmatisation and discrimination.

Employer Related Stigmatisation and Discrimination

The first group of actors that stigmatise and discriminate against diabetes patients are employers. Sami's case illustrates a typical way that employers engage in stigmatising and discriminating people with diabetes. Sami was in his forties, working for a tobacco company. He was a non-smoker at recruitment. It was company policy that all workers must smoke to live by example. So, Sami was required to smoke. Sami had a family history of diabetes but was unaware of the risks he faced. He developed diabetes in the course of his job and complications set in. Sami did not understand what was happening to him until the company referred him to a hospital. He turned up at a doctor's consultations where his diabetes status was revealed. The doctor prescribed smoking stoppage as one of his treatments. Sami protested, for fear that he will lose his job. He presented his medical records to the company revealing that he has developed diabetes and his doctor had prescribed smoking stoppage as one of his treatments. The company could not accept this and dismissed Sami a year afterwards, because his not smoking meant not complying with company regulations.

The following case elucidates a case of field observation between a worker and his company. As illustrated in Sami's case, being affected by a chronic disease exposes a person with that illness to many hours and days of absence from work in the course

of the month. Also, many company policies, like alcohol, food and tobacco companies warrant the workers to live by example by being consumers of the products that they produce irrespective of whether they have predisposing risk to developing diseases linked to these products.

Conjugal rejection

Another form of stigmatisation and discrimination observed in fieldwork was manifested through conjugal rejection. Mori's case is typical representation of one of the ways that a couple may decide to stigmatise and discriminate the partner.

Mori was a civil servant in her 30s and had been married for 7 years. She developed diabetes and was diagnosed in a hospital subject to a diabetes coma. She experienced low libido and occasionally accepted sexual intercourse with the husband but refused childbirth for fear of adverse consequences for her and the baby. The husband divorced her and married another wife.

Health Care Providers' Perspective of Stigmatisation and Discrimination

Health care providers orchestrate forms of stigmatisation and discrimination against people with diabetes in the form of maintaining discipline.

Tori was a regular attendant at a local diabetes clinic. Then he started turning up late for consultations. This went on for three months despite warnings from his consultant that he was not abiding with clinic regulation. One day he arrived late again and was refused to be controlled and consulted. His membership at the clinic was terminated. He was never seen again until it was reported a year later that he died of a stroke.

Food Prohibitions

The fourth case of forms of stigmatisation and discrimination against people with diabetes is the family. Families have their own contribution to stigmatising and discriminating against family members with diabetes.

Fami has been living with diabetes for ten years and has been receiving a lot of home-based assistance from the spouse and children. At the beginning of her treatment, she had informed her family members that she has been prohibited from eating some types of food, oil and salt. So, the family members adapted their lives to preparing her food separately from theirs. But it became too demanding on the family income, so they switched to cooking food for the entire family, removing hers and adding oil, salt and other ingredients to theirs. Two years later, she was told that she could eat everything in moderation, but the family found it difficult to come to terms with the shifting prescriptions of Fami. They suspected her of lying, ignored and continued with the pattern they had adopted. Occasionally, they accepted her requests. Fami

felt neglected and discriminated upon, but could not do much to change the situation.

Social Interactions Leading to Stigmatisation and Discrimination

The fifth example is peer stigmatisation and discrimination as depicted from the extract from case notes below. Before Ngon was diagnosed with diabetes, he had a wide range of friends with whom he did social drinking and eating. When he started treatment, he was restricted from drinking alcohol and sweetened beverages and eating variedly. His friends called him a “woman” and this looked humiliating to him and his kin. His peers rejected Ngon for subsequent social drinking and other social ceremonies because he could not more stand alcohol. Ngon settled to spending more time at home but occasionally went out with his friends and accepting to take a bitter alcoholic drink was the only thing that kept him with the group.

Discussion

Available indicators suggest a high prevalence (2-11%) of diabetes [1,19,20] related risk factors (20-50%), complications and deaths. [1,20,21] Efforts to prevent these from occurring are confounded by the ‘double burden’ of diseases in Africa [19]. Ignorance, illiteracy, poverty, the laissez-faire attitude of states and the paucity of policies and programmes for diabetes care are the huge barriers faced with tackling the rights of diabetic patients to obtaining health care [21,22].

The above cases are samples of cases that emerge in the course of diabetes care in Africa revealed by this study. There are widespread incidents of stigmatization and discrimination against diabetes patients, but these are either not reported or under-reported. Stigmatization and discrimination takes different forms, as depicted in the cases, different with those reported with HIV/AIDS and other infectious diseases [20] and are seen more or less as part of normal life. These reported incidents and many others not mentioned in this paper are responsible for the adoption of risk behaviours that expose people to developing diabetes, complications and death. A cross-section of the society shares the responsibility in breaching the rights of people with diabetes. Firstly, many health care practitioners may play on the same platform of stigmatization and discrimination with lay people, leaving the patients with fewer advocates. Secondly, many governments of low income countries, especially in Africa are required to sign conventions, reinforce existing ethics and laws where some exist and enact new ones to protect and fulfil vulnerable people’s access to health care, but they wait to respond to disastrous situations. Therefore, ending up doing what they would have acted upon to prevent a crisis situation.

Thirdly, the case of Sami and his right to work withdrawn because of his diabetes status points to the fact that both the company and Sam were ignorant of Sam’s right to health. For

that reason, it puts the health of workers in jeopardy because they may refuse to disclose their status of diabetes for fear of company stigmatisation and will run the risk of not being given attention and care that workplaces are required to offer. Equal chances and opportunities, especially to vulnerable people are jeopardised. Therefore, employers and employees in developing countries need to be educated on their right to health, the obligations of each other and the implications to health when these rights are violated in their work places, especially when it concerns chronic diseases. That Mori suffered a social crisis and eventually divorced with her husband makes one think that ignorance of family members of people with diabetes about the nature of diabetes and the complications that go with, needs to be overcome. Family members, carers of people with diabetes, especially the spouses, need to be brought to the consultation room, at least at the initial consultations and sometimes in the course of the disease, so that they can feel as being part of the care process, rather than isolating them as though they were unconcerned. Else the stigma against patients will continue and the number of court cases related to sexual dysfunction and divorce, emerging from diabetes will also increase. The very institutions of health care, purported to advocate to rights of people to health, at times violate them because they orchestrate and promote acts of discrimination. That Jean-Pierre was denied health care is a cause for concern. In addition, the ignorance of the health care provider on the fact that patients have right to health needs to be addressed.

Dismissing a worker from his job because he has diabetes, and insisting that he must continue to consume tobacco products is not only exposing the worker to complications and death, but also denying the patient right to health and life. Failure to obtain treatment for diabetes reduces the physical strength of an individual but this should not give room for a worker to be dismissed on grounds of his diabetes status. It tantamount to discrimination and refusing that person a right to health and life. The company and others that market food, tobacco and alcoholic products that contribute to increasing risk of developing chronic diseases are switching to markets in Africa where regulations are weak or not available to control them. The fact that most of the African population is illiterate, therefore ignorant, makes them vulnerable to the lure from these companies. To succeed, companies bypass labour regulations and act for their interest setting aside those of the individual workers.

The aspect of stigmatization and discrimination suffered by diabetes patients can be reduced to its minimum through vertical and horizontal education of different stakeholders, including the general population itself. This education should hinge on unveiling the stigma and discrimination suffered by people with diabetes and similar chronic non-communicable diseases. Health promotion intervention programmes should explain the right to health of all people, especially those of diabetes patients, enforcing existing legislation where there are and enacting new ones where there are

none. In addition, the nature of the disease, the risk factors and measures for diabetes care have to be explained to the entire cross-section of the population.

If many African states have to be silent with legislation and if people are left in the state of ignorance of their rights to health, it is likely that the journey of diabetes is still beginning and has a long way to go. This will be happening in countries where resources of countries will suffer another setback, as the active population will not be able to accommodate the pressure already witnessed by the over-stretched existing resources. The untold story of the Structural Adjustment Programmes (SAP) and the Highly Indebted Poor Countries (HIPC) will still remain concealed and international donors and lending bodies will have to craft new idioms and formula to address structural and social issues of health care related to diabetes. Therefore, the vicious cycle will continue, and unanswered questions will still be left untouched and diabetes and its risk factors will eat deep into the medical and social arenas, calling for more foreign aid.

African communities are well known for communal meals, but nutritional discriminations are very common in African communities when someone has diabetes. This explains the old notion of food prohibitions that were tied to diabetes care that hatched the separation of meals in families and public places. This has exacerbated the discrimination machinery set up against people with diabetes in families and communities. In the communities, people with diabetes face problems of being integrated into the society and in socializing because of the inherent belief that their disease goes with restrictions and prohibitions. For that reason, the current message of 'eating everything in moderation' still has to find its place in the diabetes care market place. If successful, it will help to eradicate the discrimination and stigmatisation suffered by patients.

It has been reported that African cases of chronic diseases will triple in 25 years [23,24] but if this ethical issue is checked from now, it may help to contain diabetes from growing out of the present proportion and enable African countries to meet the sustainable development target to reduce the burden of chronic diseases of lifestyle. When setting up policies for diabetes care, African countries should consider the fact that refusing care to an individual is not only a public health matter; it is also a human right concern. The absence of health insurance schemes in most low-income countries subdues people, especially chronic disease patients, to depend almost entirely on their kin for financial and psychosocial assistance [12] This kin relationship should be protected and harnessed as a means of preventing diabetes and improving the quality of life of those who have it, therefore building in kinship as part of the family duty and obligation. A holistic and inclusive education approach need to be established to educate health care workers, health policy makers, families, couples and employers on diabetes and diabetes risk factors and

the patient's rights to health and good quality of life. The fact that most diabetes patients speak openly about their status deserves that they should be encouraged and regarded as every normal person in the society, without attaching any stigma that may discriminate them. Openness is an issue to be exploited to lift the stigma, discrimination, and barriers to diabetes care. Though living with a chronic disease, people with diabetes always feel assertive and positive, trying to seek ways to obtain befitting treatment.

Conclusion

This paper provides evidence that there is stigmatisation and resulting discrimination against people with diabetes by a wide spectrum of stakeholders. The silence about stigmatization and discrimination in diabetes care is a huge problem to be tackled. Saying that it does not exist is like considering as a layperson that the stigmatisation and discrimination surrounding diabetes is part of normal daily life. Stigmatisation and discrimination are human rights violation issues. Human rights protection is the concern of all and it is possible when stigmatization and discrimination are overcome. By respecting these rights, we shall be preventing diabetes, diabetes complications and diabetes risk factors, and helping to provide good quality care without necessarily being health experts. Health experts should take the lead in respecting the right to health, thereby advocate for good legislation for diabetes patients in their countries. Protective measures could include enacting legislation to prohibit impelling workers to consume company products. Again, legislation should be made to protect diabetes patients from stigmatization and discrimination in employment. To achieve this, broad-based education of individuals, employers, employees, policy makers and the entire society about the rights of people with diabetes to health should be done as the key public health policy approach.

Therefore, their rights should be protected, and respected and awareness creation used to address any inherent ethical issues that compromise them. Including chronic diseases like diabetes in the global health agenda for 2030 requires that countries of Africa should widen their programmatic and legislative scope to accommodate these diseases and those who live with them. Inclusive policies, programmes and legislation in Africa will enable stakeholders of the sectors involved in supporting people with chronic diseases like diabetes to act with caution and because they have developed compelling cultures. However, this study needs to be done on a wider scale to measure the scale and magnitude of the stigmatization and discrimination that surround diabetes. Qualitative approaches alone may not serve as the only frame of reference but doing an intervention that incorporates quantitative measurements will provide more evidence for action and policy advocacy.

Acknowledgement

I acknowledge the financial assistance provided by the North-

East Diabetes Trust, International Diabetes Federation, the World Diabetes Foundation and the Newcastle University

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Competing Interest

I declare that the answers to the questions on your competing interest form are all No and therefore have nothing to declare.

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