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## FROM THE EDITOR

Dear all, it is a real pleasure for us to bring to you this 30<sup>th</sup> issue of the Innovia Newsletter. For this second half of 2018 we have contributions that remind us of how big and growing the Innovia community is. We have contributions relating topics of three different continents, reporting on rather different topics.

In relation to this, and as a response to our growing community and changes in the data privacy regulations, we have resorted to what we consider a much efficient way of communication. All of you have already received an email invitation to join a Google Group. But I let our director, Stuart Blume and Nuria Rossell, our Google Group manager explain all about it in the opening piece.

We recognize that this issue contains longer contributions than is usual in our Newsletter. But we decided to allow authors the space they needed in order to best express their stories. We are sure you that you will enjoy the read!

First, we introduce Payam Abrishami. He reflects on his previous work as a practicing physician visiting nomad patients with brucellosis in Iran. He pays special attention to patients' attitudes, behavior and lifestyle in order to comprehend the disease's spread.

Following Payam, you will find a piece in Spanish by Tatiana García-Betancourt, Adriana Díaz del Castillo and Alejandro Junca Ramírez. They reflect on the challenges, gratifications and enormous potential of



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collaborative work between healthcare practitioners and social scientists. They draw on their experience working in Colombia on issues concerning adherence to treatment as a potential place of intersection of different approaches to health in health practice. For those of you who are not familiar with Spanish we add a summary in English.

We close this issue with a piece by Emmanuel Sackey. He presents the advocacy work of the Ghana National Association of the Deaf, aimed at including sign language interpretation services in the national healthcare system. Not without facing difficulties for implementing these initiatives, the GNAD has initiated two projects, which Sackey addresses in his piece.

We hope you enjoy this latest issue of the Innovia Newsletter. If you have any feedback, events you may want to share with Innovia's readership or if you would like to contribute with a piece in one of our issues, please do not hesitate to contact the editor.

With best wishes,

María Fernanda

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## **News from Innovia**

**Stuart Blume and Nuria Rossell**

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As a result of the new data privacy regulations in the E.U. which came into force on May 25th, we wanted to be sure that our privacy policy conforms with such regulations, while looking for an efficient way to reach you and deliver our newsletter.

Although Innovia doesn't collect any information about anyone, other than the names

and e-mail addresses of Newsletter recipients, we want to ensure we act in accordance with the law. This means that because your name is on the Newsletter distribution list we must ask you to tell us that you're ok with us storing this information for the purpose of sending the newsletter.

## **Why a Google Group?**

An earlier attempt to contact a number of readers through regular mail came up against Google's spam blocking technology, due to the number of recipients. To avoid this situation, and to be sure that all of you who want it do receive the newsletter, we have created the Innovia Google Group for sending our communications.

In practical terms this doesn't change anything for you. Your names and addresses remain concealed from the other members as was the case previously. Also, group members will not be able to send messages through the Group - it's strictly for the Newsletter.

Possibilities for future growth and alternatives for using this group in a more interactive way might be worth exploring in the longer term. However, your involvement in the group will be kept as simple as it's been till now... unless of course you'd care to offer some ideas. But to reiterate: the main purpose of the group is the distribution of the Newsletter.

## **Our request**

Innovia is not trying to compete with social media formats and we do not depend on followers or 'likes', although we do hope that you find our newsletters interesting and worth sharing. If you think colleagues in your network could also enjoy or perhaps even contribute to the Newsletter, feel free to send them an invitation to join our group so they can receive

the Newsletter, or email us so we can contact them and ask their permission to send it to them.

We appreciate your support and look forward to sharing coming Newsletters

Stuart Blume and Nuria Rossell

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## **Brucellosis in Iranian migratory nomads What was at stake in the disease control program?**

Payam Abrishami

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### **Background**

Brucellosis is a bacterial infectious disease. It is also called 'Malta fever'. It is basically an infection of domestic animals but may involve human beings as well. The first recognised brucella infection in a human being was reported in 1898 (Nicoletti 2002). Those affected by this infection have quite often a close contact with domestic animals. Brucellosis is transmitted to humans from the animals through ingestion of contaminated raw milk and its derivatives or through direct contact with infected animals (e.g., slaughtering, breeding, birth giving). The most common route of transmission in human is via consuming infected dairy products. Brucellosis in humans has a significant burden. It is a long-lasting infection varying from some weeks to several months. It may also involve several body organs including kidneys (a multi-system infection). The main symptoms are prolonged fever, long-lasting body pain specially bone and joint pain, night sweats, weight loss, and symptoms of the involvement of a particular body system or organ (Honarvar et al., 2017; Jamili 1999). The diagnosis is based on clinical symptoms and certain laboratory tests. Clinical

treatment usually involves using multi-potent antibiotics for a relatively long period of time (at least eight consecutive weeks).

In Iran, brucellosis has long existed (i.e., an endemic disease) with a considerable rate of emerging new patients (the so-called incidence rate). In 1988, Iran had the highest incidence rate of brucellosis among the Mediterranean countries, namely, 133 patients per 100,000 of population (Refai 2002). In 2000, the incidence rate reduced significantly to about 24 per 100,000 of population; but later on (2005) an increase up to 39 has been reported.<sup>i</sup> In general, brucellosis is more common in men, in the illiterate, in the poor, in rural (compared with urban) areas (Salari 2003) and in early summer (Roushan 2005). It is also not uncommon in children as once believed (Alavi et al. 2007).

Tackling brucellosis is one of the public-health priorities and challenges in Iran due to its considerable disease burden (Ayatollahi 2004; Salari 2003). In fact, this infection causes numerous clinical consequences for patients and interferes with their everyday lives sometimes seriously. In addition to the burden on individual patients, brucellosis is also associated with a major financial burden on the health care system.

Studies in Iran show that migratory nomads are particularly vulnerable to brucellosis as their lifestyle implies a close contact with domestic animals including drinking raw milk. They are a highly infected population (Alavi et al. 2007), yet a neglected population (Honarvar et al., 2017). Almost all of the patients have the history of unsafe dairy consumption and many have skin contact with domestic animals (Alavi et al. 2007; Salari 2003). Among nomads, it is possible to observe multiple patients within one family, especially when an unsafe dairy product is involved (Alavi et al. 2007).

## **The National Brucellosis Control Program**

In Iran, brucellosis is a priority infectious disease for which there is a national program for control and surveillance, set up by the Ministry of Health. I hereafter refer to it as National Brucellosis Control Program; NBCP. The NBCP was implemented by the Network of Governmental Medical and Health Centres (public clinics) [Markaze Behdasht]. It involved the following activities: case finding (detection of susceptible patients in the community) by the community health workers [Behvarz] and the health staff of public clinics, referring susceptible cases to the clinic, usually by the health staff and/or private physicians, diagnosis, clinical treatment<sup>i</sup>, monitoring patients during the treatment period (follow-up), referring complex cases to higher medical levels (certain medical specialists and hospitals) if necessary, instructing patients, and informing the public (in endemic areas). Physicians and the health staff of public clinics received regular training, instructions and feedbacks as to how to perform these tasks and report these activities to higher authorities. For each of the above tasks, there was usually a defined protocol that the health staff and physicians had to follow. Within NBCP, all services offered to (suspected) brucella patients in public clinics were free of charge. These included physician consultation, laboratory tests, all necessary medications (antibiotics), follow-up visits, and patient counselling.

## **A reflection on the disease control program**

This essay is based on a reflection on my previous observations and experience as part of NBCP. Between 2002 and 2005, I was involved in NBCP as physician of public clinics of Firoozabad and Farrashband; two adjacent towns in the south of Fars Province. Every year,

these towns and their vicinity hosted large groups of migratory nomads who reside there in winters and springs and left for the Northern provinces in summers. In that area brucellosis had long been a common disease and the nomads were, indeed, the main sufferers (Honarvar et al., 2017). For writing this essay, I used some unstructured notes from conversations I had with my brucella patients and the health staff when I was a practicing physician there. I then reflected on these notes with the help of anthropological insights that I acquired later. This essay is, therefore, a reflection on NBCP and not the result of an empirical study or ethnographic research.

The NBCP had a strong medical-scientific foundation in its design and implementation, not least, by providing patients with generous medical care for free. It was also a reasonably well-organised and well-implemented plan in terms of cooperation between the private sector and public clinics, coordination with higher authorities, and data registry given the limited available facilities and (human) resources at the time. However, I argue that there was an important limitation. Within NBCP sociological considerations were largely absent, in particular, little attention was paid to the lifestyle, attitudes, lived experiences, and collective behaviours of the most vulnerable population, namely, the nomads.

Within NBCP, we already knew that the nomads are a high-risk target group and should receive specific attention: they are in close contact with domestic animals; they are a migratory (unsettled) population and sometimes reside in inaccessible remote areas; they are important active transmitters of brucellosis into the local communities through selling their potentially contaminated dairy products (Sheik-Mohamed 1999). We did also know that

migratory nomads have a distinctive lifestyle. Yet, we (health care staff and policy-makers) did not pay adequate attention to understanding the social-cultural dimension of their vulnerability to brucellosis. We did not take into account that the generic measures employed to control brucellosis in a settled community may not work for the unsettled population such as nomads (ibid.). We focused more on 'the disease' rather than 'the patient', neglecting the humane dimension of the illness and its spread (Honarvar et al., 2017). We failed to acknowledge the importance of such understanding because we were not aware or perhaps did not believe that bringing cultural issues as such into consideration could make any difference within a disease control program. We were probably convinced that since the NBCP is a well-designed program medically and organisationally and since there are some instructions for patients available, it must work. We did not consider sufficiently the social realities underlying the nomad's vulnerability to brucellosis. In short, within NBCP we did not have sufficient sociological insights in approaching this high-risk and susceptible group of patients.

In the next part of this essay, I aim to highlight the importance of an in-depth understanding of the problem by drawing on nomads' emic views about brucellosis. I re-examine a number of personal observations from the time I was part of NBCP as a practicing physician. As mentioned before, these observations are just reflections in support of taking sociological considerations into account when designing and implementing a disease control program.

## **A sketch of nomads' perspectives on brucellosis**

### *a. Nomads' views about their dairy cattle*

Cattle are closely interwoven into the nomadic lifestyle. For nomads, cattle are respected, not just because they are a means of earning and living but also due to a sense of companionship that a close contact with the cattle may bring about. "For nomads, cattle are everything" was a typical opinion of a nomad patient.

Drinking fresh raw milk (just taken from the cattle) was a very common practice in that area. Being accustomed to their cattle, the nomads did not attribute a miasmatic character to raw milk and often believed it to be clean. When I asked the patients why they had drunk unheated milk, I realised that fresh, raw milk was considered warm enough at the animal's body temperature and was, therefore, perceived as clean.

Another common practice I witnessed was giving cow's colostrum<sup>iii</sup> to the newborns. The assumption that newborns may benefit from cow's colostrum as a tonic supplement for mother's milk was prominent in some nomad families. If the cow is infected, consuming colostrum can be associated with a higher probability of brucella transmission than regular milk due to its more concentrated bacterial content. This explained brucellosis in newborn in that area. Although brucellosis in newborns is generally rare, in that area I experienced several newborns with brucellosis. It should be noted that treatment of newborn patients is much more difficult than adults because of the vague symptoms and the serious adverse effects of antibiotics in newborns.

Inhorn (1990) emphasises the importance of many culturally prescribed patterns of behaviour in spreading infectious diseases. Similar to what Inhorn examined in another

infectious disease (the hydatid infection) in Kenya, in case of brucellosis, the nomads may not associate the disease with their cattle. They may also not consider cattle as the source of infection. Some patients told me that they had faced abortion in their livestock. This is a strong indicator that the animal is infected. In that case, they commonly ascribed animal's abortion not to brucellosis but to other causes including misfortune or evil eye.

These observations provide an explanation as to why nomads are vulnerable to brucellosis. Health educational/promotional endeavours within NBCP at the time did little to address this aspect of disease transmission, let alone help change patterns of potentially risky behaviours.

*b. Nomads' views about brucellosis, the disease symptoms, and treatment*

The ways the nomads perceived brucellosis and its symptoms are also noteworthy. In an epidemic, when a disease is becoming common in a community, increased occurrence might create awareness and make people more cautious regarding the disease. Unlike epidemics, brucellosis was endemic and has long been common in the community. There seemed to be a tendency for people to 'trivialise' the disease and its symptoms in one way or other. Many brucella patients neglected the presence of the disease and its seriousness. The nomads had often been living in extended families in which experience of the disease by one of the family or tribe members was quite common. To that end, there was a vast array of narratives and lay explanations accumulated over time about the causes of the disease, the ways to cope with it, and the local remedies for it. In this context, living with brucellosis was associated with a reduced cognitive sensitivity; somehow an

'acceptance' within the community and as such in the mind of new patients. In the words of a patient: "being nomad means having Malta fever".<sup>iv</sup>

Another related process that facilitated neglecting brucellosis was the attribution of symptoms to less serious conditions such as common cold. "I've been taking acetaminophen and the pink pill [Ibuprofen, a pain killer] every day to lessen my body pain and to continue weaving carpet and pasturing cattle. But these pills cannot stop my 'cold'." This quote shows that the patient did not attribute a prolonged set of symptoms to brucellosis, thereby hoping to be cured by simple home remedies or self-prescribed pain killers. Even if they became suspicious of having a disease beyond a simple flu, they perceived it as an infectious disease in a general sense of the word. In this case, they had often taken antibiotics (such as Amoxicillin capsules), which were perceived as a generic cure and were accessible sometimes without prescription. However, this antibiotic was not suitable for treating brucellosis.<sup>v</sup>

Patients also often attributed the symptoms of brucellosis to their tough every-day life condition. One of the most common symptoms, namely body pain, was simply ascribed to hard daily chores and difficult lifestyle. Prolonged malaise, fatigue, sweating, and weight loss – again important symptoms of brucellosis – were also often understood as results of poverty-related malnutrition.

Nomad patients, therefore, did not usually become suspicious of getting brucellosis and if they did, they were not driven by this concern to seek special medical attention for brucellosis. It was difficult for many of patients to recognise the onset of disease because they perceived the symptoms as a part of their everyday 'life-as-usual' (Koss-Chioino 1997).

This perception renders a notable contrast with their own alleged over-familiarity with brucellosis as an endemic disease in their community. Fieldwork studies are needed to explain this contrast.

A sense of the ‘usualness’ of brucellosis within the nomads’ community and a subsequent desensitisation to the disease’s severity also interfered with the treatment of the patients who were already diagnosed with brucellosis and monitored within NBCP. They often suffered from a poor adherence to treatment (not using antibiotics regularly until the end of the treatment course).<sup>vi</sup> This, in turn, resulted in a failure in the completion of their clinical treatment followed by a disappointment as to why all those body pains and other awful symptoms came back again. Recurrence of the infection and antibiotic resistance were then two potentially serious consequences.

#### *c. Nomads’ communication with the health personnel*

That the NBCP was not attentive enough to capturing the nomads’ own views was also evident in the interactions between nomad patients and health personnel, particularly with the newly graduated physicians and nurses coming from other parts of the country as part of a mandatory duty assigned to the health care staff.<sup>vii</sup> These somehow ‘non-native’ personnel were often unfamiliar with the nomads’ culture and had difficulties communicating with them, sometimes also because of a language barrier (if they were unfamiliar with nomads’ Turkish dialect).<sup>viii</sup> Similar to what Koss-Chioino (1997) examined, the nomad patient’s culturally-laden explanation of the disease, its symptoms, and local remedies sounded exotic to the non-native staff and were often easily ignored (Sheikh-Mohamed 1999). Indeed, non-native health staff sometimes held the view that the nomads’ beliefs

and practices do not *matter* to their medical problem (brucellosis).

The local health personnel and the community health workers, on the other hand, were more familiar with nomads’ culture and dialect and were well able to understand nomads’ practices. However, their communication with nomads were rarely sufficiently in-depth, and did not capture the attitudinal and behavioural aspects that made them vulnerable to brucellosis. It was quite often far from a systematic approach and incapable of making impact as a distinctive behavioural intervention in the nomads’ community. Simultaneously, patient education by local health personnel was commonly limited to a number of brief theoretical instructions, such as how to make physical contacts with animals safer, e.g., by wearing a mask, how to take medications and deal with their side effects. Such information was, in itself, essential and valuable but could not target the core of the risky behaviours underlying nomads’ vulnerability. They could hardly end up with an effective attitudinal/behavioural modification as they were usually framed in an imperative ‘do/don’t do’ discourse. The cultural, behavioural, and attitudinal features were, thus, not crystallised enough in the patient counselling. If simply conveying an imperative message such as “do boil the milk” had worked, the disease would no longer have been endemic in the area.

#### **The contribution of health sociology**

The above-mentioned observations do not indicate that the NBCP was pointless. Rather, they highlight what was at stake in the infectious disease control and surveillance program. This reflection on my earlier experience helps me better understand why it is difficult to tackle the disease spread effectively without paying decent

and systematised attention to the patients' culture, practice and lifestyle. This is the point to which medical sociology and anthropology can contribute significantly. With such an anthropological 'eye', we could have better understood the 'problem', i.e., why the nomads were vulnerable to brucellosis, perhaps before rushing to implement the 'solution' (namely the provision of generous medical care for free). Of course, I am describing the situation of more than a decade ago and the NBCP, I do not doubt, must have improved by now. I no longer follow the developments of this program anymore but I sincerely hope that health sociologists have now been involved in this and other public health programmes in the country.

The insufficient sociological insights in implementing the NBCP at the local community level (where I worked) indicates that such insights had probably been missing – in the first place – at the level of program design. Looking backward from the implementation to the outset of NBCP, it seems that the program designers had already opted for a medically-oriented approach with some health educational measures being no more than an 'add-on' to that core. However, in designing a public-health program, an emphasis on behavioural interventions could lead to more effective and probably less costly policies than an emphasis on fighting the disease. The reason is that the underlying cause of disease spread in humans is principally attitudinal and behavioural rather than clinical or microbiological. Vulnerability (engagement in a risky behaviour), can therefore, best be tackled by treating the 'human' component equally with the 'disease' component of 'patient'.

This can be accomplished by 'grounding' a disease control program such as NBCP on a principally behavioural (preventive) foundation.

This approach 'prioritises' the provision of culturally-competent health education and promotion adaptable to the local culture and practices. Designing and implementing a disease control program as such demands social-scientific knowledge and expertise in addition to medical sciences.

### **Conclusion**

In this essay, I reflected on my earlier personal experience with a national program to control brucellosis in the south of Iran, and highlighted what was at stake within the program. Despite considerable organisational efforts and generous funding dedicated to the program, it failed to adequately take into account the culture, lifestyle, and perspectives of the most vulnerable population – the nomads – underlying the disease spread.

I hope to inspire (health) sociologists to engage with public health and health policy issues more proactively by conducting ethnographic studies and communicating the findings with health policy makers and medical professionals. Insights from health sociology are crucial to enhance the effectiveness and the success of a disease control program. This involves an analysis, in which a public-health policy such as a disease control program is not merely approached with medical knowledge but also framed as a social enquiry. Health sociology can provides us with a comprehensive understanding of the 'why' and the 'how' of a public-health problem being a problem as such. Accordingly, the proposed health policy solution would – thanks to the social scientific insights – prioritise "knowing the community" as its departure point.



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## Notes

<sup>i</sup>Salamat News website:

<http://www.salamatnews.com/ViewNews.aspx?ID=4856&cat=7>  
(Accessed: 03.12.2017)

<sup>ii</sup> The treatment usually included a combination of two or three strong antibiotics and compulsory follow-up visits every four weeks. The standard treatment protocol for adults at the time consisted of Rifampin capsule 300 mg two times a day with one or two of the followings: Doxycyclin capsule 100 mg two times a day

or Streptomycin 1gr injection once a day or Co-trimoxazol two tablets, three times a day.

<sup>iii</sup> Colostrum is the first milk produced by the mammary glands. It is rich in proteins and minerals and is produced just after delivery of the newborn and before the production of regular milk.

<sup>iv</sup> This quote has also a connotation that brucellosis is very common among nomads.

<sup>v</sup> There are many social and cultural processes related to the use of antibiotics, such as penicillin in Iran. This can be an interesting and perhaps necessary focus for further medical-sociological studies.

<sup>vi</sup> In the setting which I worked, poor adherence to the treatment had also explanations beyond the scope of this essay. These included: lack of access for patients settled far from the clinic, insufficient education especially for children, elderly, and women, and not showing up for follow-up visits again partly because of residing in distant areas. Very often a family member came to the clinic and just asked for some (free) medications on behalf of an already diagnosed patient.

<sup>vii</sup> According to a national plan for redistributing human resource, the government had obliged graduates of medicine and para-medicine to work up to two years outside large cities and in rural and remote areas.

<sup>viii</sup> Nomads in that area spoke a regional Turkish dialect. It was often hard to communicate with women and the elderly in official language, Persian.

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## PERSPECTIVAS SOCIALES EN LA EDUCACIÓN Y EN LA PRÁCTICA EN SALUD: UNA NECESIDAD DE INTEGRACIÓN

Tatiana García-Betancourt, Adriana Díaz del Castillo, Alejandro Junca Ramírez

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## Summary

This article reflects on the integration and collaboration of social sciences with medical practice and health education. From our experience as clinicians, researchers and teachers, we discuss the need to recognize other disciplines and create bridges between them. We present the study of adherence to treatment as a potential place of intersection in health practice. We suggest possible scenarios of integration where different disciplines can come together

and collaborate in addressing health problems from a practice perspective.

### **Disciplinas y diálogos**

Han pasado varias décadas de discusión académica internacional sobre el valor que tiene para la salud el conocimiento generado por las ciencias sociales, específicamente por disciplinas como la antropología médica y la sociología y por las metodologías cualitativas. Se ha argumentado por la necesidad de llevar efectivamente ese conocimiento a los profesionales de la salud y a los escenarios donde se toman decisiones. En ese proceso, se han descrito los diferentes retos y desafíos que implica este diálogo (Hemmings, 2005; Shand, 2005). Incluso se han señalado “culpables” de esa falta de integración; no es de extrañar que tanto la antropología como la medicina hayan resultado señaladas en ese proceso (Hemmings, 2005; Shand, 2005).

Hoy en día, vemos que esa discusión sigue siendo relevante en Colombia, pues a pesar de que desde la investigación en salud se han llevado a cabo estudios multidisciplinarios que integran diferentes enfoques y puntos de vista todavía nos encontramos con situaciones en las que se piensa que la investigación en salud debe ser abordada solo por profesionales de la salud.

A continuación presentamos dos escenarios en donde tienen lugar estos desafíos, pero que al tiempo presentan oportunidades para el diálogo: el primero desde la educación y el segundo desde la práctica clínica médica, específicamente en el tema de adherencia a tratamientos. Esta reflexión ha sido parte del trabajo conjunto y colaborativo entre dos antropólogas y un médico clínico, quienes por cuatro meses hemos estado re-pensado la adherencia y puntos de unión prácticos desde nuestras disciplinas.

### **Empezar desde el principio**

Los programas de medicina en Colombia se han abierto a incluir cursos o módulos de investigación cualitativa, antropología de la salud o medicina social desde hace también varias décadas. Actualmente se incluyen en cursos de posgrado en salud pública o epidemiología. Sin embargo, persiste el desafío que esta integración se dé más allá de módulos aislados o electivos, y ocurra de manera más transversal. Por ejemplo, a través de una mayor incorporación de literatura con metodologías cualitativas o métodos mixtos en cursos clínicos; de motivar la búsqueda de información fuera de bases de datos médicas; de realizar eventos o jornadas interdisciplinarias en las escuelas de medicina y de ofrecer incentivos concretos para la colaboración con mayor financiación, específicamente dirigida a estudios interdisciplinarios en salud.

Desde nuestra experiencia, hemos tenido estudiantes que no saben dónde empezar a buscar “literatura cualitativa”. Algo que puede parecer un detalle menor, pero que constituye un llamado de atención. Nos habla de un aislamiento disciplinar que tiene consecuencias prácticas. Una limitada exposición de los(as) estudiantes a otras perspectivas y enfoques, se traduce en clínicos(as) que no cuentan con suficientes herramientas para la interacción y comunicación médico(a)-paciente y para lidiar con perspectivas, valores, expectativas, experiencias, necesidades y deseos sobre la salud, diferentes a los que aprendieron en la facultad. El mayor problema es quizás que son precisamente los pacientes quienes padecen en mayor medida las consecuencias, según lo han descrito varios estudios sobre el tema (Haskard K & Di Matteo, 2009). Entonces el asunto está también en cómo llegar a quienes están inmersos en la práctica clínica del día a día y quienes en

últimas están más cercanos a las vidas de las personas.

Pero al igual que con los(as) médicos(as) en formación y en parte como consecuencia de eso, en nuestro quehacer como investigadoras, docentes y clínico, seguimos encontrando que el mundo de la clínica permanece bastante ajeno al conocimiento que se construye sobre la salud desde otras disciplinas. Hace más de 10 años, Alex Shand argumentó que esto era un asunto de ego disciplinar, de falta de interés y de capacidad de reconocer el valor de otras perspectivas (Shand, 2005). En este caso, nos interesa atender el efecto que esto tiene en la práctica y no nos detendremos a examinar sus posibles múltiples causas. Lo que vemos en últimas en nuestros colegas médicos(as) es un desconocimiento de que estas posibilidades existen y de que la literatura en estos temas lleva décadas disponible.

### **Un punto de anclaje**

Pensando en conjunto sobre posibles escenarios para acercarnos al mundo de la clínica, llegamos al tema de la adherencia. La adherencia a un tratamiento ha sido definida de diferentes maneras a lo largo del tiempo. Históricamente se ha discutido el rol de cada uno de los actores que intervienen en este proceso; inicialmente se entendía como el cumplimiento (*compliance*) de una prescripción, desde una mirada pasiva de seguimiento y obediencia de un paciente a una recomendación (Vermeire, Hearnshaw, Royen, P, & Denekens, 2002), Actualmente, la definición y el estudio de la adherencia se ha interesado en entender los puntos de encuentro entre médicos(as) y pacientes, el diálogo y la comunicación, la concordancia, la cooperación y la toma conjunta de decisiones (Vermeire et al., 2002). Es así que hoy en día la Organización Mundial de la Salud define la adherencia como

“el grado en que el comportamiento de una persona —tomar el medicamento, seguir un régimen alimentario y ejecutar cambios del modo de vida— se corresponde con las recomendaciones acordadas de un prestador de asistencia sanitaria” (WHO, 2003).

Lo anterior se ha planteado desde lineamientos internacionales, nacionales y guías de atención y además se ha acompañado de un aumento en las discusiones entorno a la humanización de la atención en salud y la medicina basada en el paciente (Todres, Galvin, & Holloway, 2009). Por ejemplo, la OMS ha identificado cinco dimensiones interconectadas que influyen en la adherencia: 1) el sistema de salud (acceso al sistema y a medicamentos, planes de seguro de salud, asistencia sanitaria y servicios accesibles), 2) los factores socio-económicos (nivel educativo, desempleo, edad, género y ubicación), 3) el tratamiento (duración del tratamiento, tratamientos anteriores y efectos beneficiosos y secundarios), 4) la enfermedad (síntomas, discapacidad, progresión y la disponibilidad de tratamientos efectivos) y 5) el paciente (conocimiento, actitudes, creencias, percepciones, red de apoyo y las expectativas) (WHO, 2003). A su vez, desde las ciencias sociales, se ha estudiado por ejemplo: la experiencia de la enfermedad, el significado del cuerpo y las motivaciones que influyen en el comportamiento de los pacientes y en el seguimiento de un tratamiento .

Así, se reconoce que seguir las indicaciones terapéuticas y realizar cambios en la vida cotidiana es complejo, dinámico y difícil, que incluye tanto a los pacientes, familiares, personal de salud, aseguradoras, laboratorios farmacéuticos y sistema de salud en general. No hay una sola estrategia de intervención que sea efectiva para todos los pacientes que padecen una misma enfermedad. Por esto, los

lineamientos invitan a que las intervenciones que se dirigen a la adherencia se adapten a las demandas particulares relacionadas con la enfermedad y el paciente (WHO, 2003). Para lograr esto, se hace un llamado a analizar la adherencia como un proceso dinámico, a entender al paciente desde su contexto y comprender cómo ocurre la toma de decisiones; un análisis que no solo se centre en el paciente como el responsable, sino que analice los determinantes de la no-adherencia, la interacción de múltiples factores y vaya más allá de la idea tradicional de cumplimiento (WHO, 2003).

### **Buscando escenarios de encuentro**

Consideramos que la discusión y planeación de estrategias frente a la adherencia se presenta como un escenario prometedor para un enfoque multidisciplinar y un trabajo conjunto de profesionales de la salud, investigadores(as) y tomadores de decisiones de diferentes disciplinas (WHO, 2003). Lo vemos así por al menos tres motivos: (1) es un asunto cuya comprensión ha evolucionado a lo largo del tiempo y ha sido ampliamente estudiado desde la epidemiología, las ciencias sociales y las metodologías cualitativas, (2) hoy en día sigue siendo un reto para la salud pública, la clínica, los pacientes, sus familias y los sistemas de salud y (3) unir conocimientos teóricos y prácticos sobre la adherencia puede fortalecer la práctica clínica, mejorar los desenlaces en salud y, en últimas, traducirse en mayor seguridad y bienestar de los pacientes; además, posibilitar que los avances en la tecnología biomédica cumplan su objetivo de reducir la carga de varias enfermedades (WHO, 2003).

Sin embargo, como se dijo anteriormente, los estudios, discusiones y resultados desde diferentes disciplinas siguen sin ser ampliamente difundidos en el mundo de la clínica aún

cuando, una vez conocidos, podrían ser altamente valorados.

Las preguntas que surgen son entonces ¿cómo acercarse a profesionales de la salud para hablar sobre adherencia desde un enfoque social y cultural? ¿Cómo llegar al mundo de la clínica por fuera de escenarios académicos formales? ¿Cómo transmitir el mensaje para que no se reciba como ajeno o poco práctico? En el marco de esta discusión, a continuación planteamos algunas sugerencias a partir de nuestra experiencia trabajando en colaboración.

- El que llevemos décadas sin lograr establecer canales de comunicación sostenibles, nos habla de que hay que cambiar de estrategia. En nuestro caso, esto implicó tomar la iniciativa de iniciar la conversación de dos antropólogas con un clínico.
- Hemos encontrado que sí existe la disposición de un número de médicos(as) clínicos(as) para participar en escenarios de discusión desde “nuevas” perspectivas. Una vez las personas se exponen a estas miradas, y si son receptivas al tema, son claves para abrir nuevas oportunidades: facilitan que el mensaje llegue a personas, instituciones y espacios a quienes otros profesionales no tienen fácil acceso. Por ejemplo, asociaciones médicas, instituciones de salud o congresos médicos. La comunidad médica puede ser más receptiva cuando la iniciativa viene de sus pares.
- Buscar escenarios propicios para este tipo de reflexiones. Es decir, llegar a la consulta y salir de la academia. Los espacios que hemos identificado son los cursos de educación continua a clínicos(as), especialistas y sub-especialistas, congresos y simposios. Este

ejercicio puede proveer desafíos adicionales, como lo es moverse en escenarios “incómodos” o que se han percibido como problemáticos. En nuestro caso esto equivalió a contemplar eventos auspiciados por la industria farmacéutica. Estos son escenarios acostumbrados para los(as) clínicos(as) y permiten el acceso a un número importante de especialistas. Frente a este reto nos surgen aún varias preguntas, pero hemos encontrado que el diálogo abierto y tener objetivos y expectativas claros son un buen punto de partida para tomar decisiones.

- Enfocar el tema de la adherencia a partir de situaciones o casos “reales” que sean cercanos y relevantes para los(as) clínicos(as). Para esto es indispensable trabajar en colaboración con médicos(as) en ejercicio.
- Puede haber oportunidades de difundir información a través de boletines y circulares de sociedades médicas, pero también es importante comunicar a través de otros tipos de piezas como videos, notas de política y documentos de posición que usen un lenguaje común y accesible.

Estas son algunas sugerencias que planteamos desde nuestra experiencia, en la cual queremos construir puentes y visibilizar grandes hallazgos que se tienen desde diferentes disciplinas, que pueda colaborar para solucionar problemas latentes. Creemos que las problemáticas actuales y su complejidad, son escenarios para pensar en la integración y proponer miradas distintas, mas allá de una sola disciplina.

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## **BRIDGING THE COMMUNICATION BARRIER TO ENHANCE HEALTHCARE FOR THE DEAF COMMUNITY**

**Emmanuel Sackey**

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### **Introduction**

Out of the current 29.6 million people in Ghana, 888,000 (3 percent) are estimated to be persons with a disability. Approximately, 15 percent of the disabled population are deaf or hearing impaired whereas 13.7 percent are estimated to have speech impairment. For the deaf population, communication with the wider population constitutes the major obstacle to participation in social life and access to social services. This challenge become more pronounced in the healthcare sector where there exist no institutionalized sign language interpretation or assisted technology services that facilitate communication between medical professionals and deaf patients. Estimates of the Ghana National Association of the Deaf (GNAD) indicate that between 2009 and 2011 about 57 members of the association lost their lives. While the association admits that death is a natural phenomenon, a section of the membership attributes the relatively higher mortality rate to the communication barrier they encounter at the hospitals.

From this perspective, there is higher probability that, owing to the communication barrier between the deaf and medical doctors, nurses, physician assistants etc., the diagnosis and treatment of deaf patients may sometimes be inaccurate. Since 2009, a proposal for integration of sign language interpretation services into the national healthcare system has been among the core advocacy issues of the GNAD. Even though

parliament passed the National Disability Act (715) in 2006 and ratified the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) in 2012, the provisions of these legislations have not seen any implementation. As a strategic response, the GNAD has initiated two projects that have the potential to enhance the deaf community's access to healthcare. The initiatives include a sign language training program for medical assistants in selected public hospitals, and the introduction of remote video sign language interpretation service, in collaboration with Vodafone Telecom.

### **DICAP Project and Healthcare**

Within the past decade, the GNAD has undertaken various projects to make healthcare inclusive for the deaf population. These include awareness campaigns and training programs on malaria, tuberculosis HIV/AIDs, sexual and reproductive health etc. which were specifically designed for the deaf. The aforementioned projects were made possible through a collaboration between GNAD and relevant state institutions and funding from various donors. In 2010, the GNAD began the first phase of the Deaf Information and Communication Access Project (DICAP). A component of the project focused on sign language training program for nurses and physician assistants from selected hospitals in the Ga East District, of the Greater Accra Region of Ghana. The objective of the project was to integrate sign language interpretation services into the healthcare system. Two assumptions underpinned the strategy. The first was to reduce cost by offsetting the fee which would otherwise be paid to professional interpreters. Secondly the project was intended to make sign language interpretation services more readily available for deaf patients, especially in times of emergency.

With financial support from the UK Department for International Development (DfID), the GNAD began the phase of the DICAP project which sought to build advocacy Capacity of leadership of the Deaf community in the Ga East Municipality. The second phase of DICAP (the Health Component) began in 2011. In the first quarter of the year, the GNAD organized the first segment of the sign language training at Madina, for 15 nurses and medical assistants from four hospitals in the Municipality. The participants were taught foundation courses in American Sign Language (ASL) which is the dominant mode of communication for the deaf community in Ghana. A follow up training was organized in the latter part of the same year.

Between 2013 and 2015, the initiative was replicated in Accra and Kumasi, with financial support from STAR Ghana, an Accra based multi-donor agency. The latter phase involved a collaboration with two major hospitals, namely, the Accra Ridge Hospital (the Greater Accra Regional Hospital) and the Kumasi Okomfo Anokye teaching hospital, in the Ashanti Region. A total of 24 nurses and physician assistants from the two hospitals were trained in sign language. This raised the total number of healthcare providers trained in sign language, under the DICAP project, to 39, with the expectation of making healthcare accessible to the deaf community. Even though it was expected to be replicated in other districts, resource constraints have not made the sustainability and replication possible.

### **Remote Video Sign language Interpretation Services**

On 11<sup>th</sup> May 2017, Vodafone became the first Telecom company to initiate a video sign language interpretation service in Ghana. The pilot initiative in the Greater Accra Region

follows the advocacy engagements and collaboration between the GNAD and Vodafone. It is relevant to emphasize that even though the service can be used to enhance communication between non-deaf healthcare providers and deaf patients, it was not specifically designed for exclusive usage in a hospital setting, but to enhance general communication and information access for the Deaf. According to a staff member of Vodafone, there are currently no remote video interpretation devices installed at the hospitals. This means that deaf persons who wish to use the facility must use their own smart phones. By dialling the designated code, deaf persons are able to access the services of remote sign language interpreters stationed at Vodafone.

### **Outcomes**

Despite persistent attempts to invite deaf persons to share their experience, research participants who have used the services in hospital settings were not available. Neither was data available on the number of deaf persons who have benefitted from the two initiatives. With regards to the DICAP project, the Director of GNAD emphasized that even though the hospitals were expected to keep such records, lapses in the project monitoring and evaluation system have made impact assessment complicated. In a similar vein, even though the sign language interpreters at Vodafone maintained that some deaf patients have used the remote video interpretation services to enhance their access to healthcare, they (Vodafone) do not currently have records on the number of deaf persons who have used the new technology for health purposes.

Nonetheless, the attempt to mainstream sign language interpretation services into the healthcare system is a laudable one. The initiative has the potential to make healthcare

inclusive for the deaf population. Besides, it has the potential to reduce costs in a context where the state has no policy to accommodate the communication needs of deaf patients. However, scope of geographical coverage has been very limited as the intervention has so far been confined to only 2 out of 10 regions and 3 out of 254 districts. Besides, only 6 out of over one thousand state hospitals have been covered. Furthermore, the areas under coverage make the projects' urban bias apparent. Additionally, the duration and content of the training may not guarantee the trainees' attainment of the requisite standard of sign language proficiency. However, since *half a loaf is better than none*, the attempt could be considered as *a first aid* or complementary rather than the main solution to inclusive healthcare for the deaf population.

### **Towards a More Effective and Sustainable Intervention**

The GNAD is a voluntary self-help association of deaf persons and a non-governmental organization (NGO) with about 10,000 members (out of an estimated 150,000 deaf people in Ghana). As a voluntary organization, it has no obligations towards the entire deaf population. Despite the willingness of the GNAD to *help*, it has very limited resources and is highly donor dependent. From a legal perspective, the social contract underpinning the nation-state, is between the government and the citizens. Therefore, even though the interventions of NGOs and other voluntary organizations are laudable the state has no statutory obligations to them. The role of voluntary organizations such as the GNAD should therefore be complementary rather than a substitute for state intervention.

Apart from the control over the national treasury, the institutional structures of the state

permeate the entire country, whereas the operation of NGOs are restricted to a few urban and rural districts. It is therefore paramount for the Ministry of Health to consider policy measures that would ensure the mainstreaming of sign language interpretation services into the national healthcare system. The National Disability Act (715) and the UNCRPD make such a state intervention obligatory. Finally, it is logical to posit that, in the context of a very limited supply of sign language interpreters, state support for professional sign language training, and a technology driven remote/video interpretation service hold the key to accessible healthcare for the deaf population.

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