




TB & CULTURAL COMPETENCY

Notes from the Field

NEW JERSEY MEDICAL SCHOOL NATIONAL TUBERCULOSIS CENTER Issue #2

Dose by Dose

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Introduction

This case is from a Public Health Nurse in a large Wisconsin city. The patient, who we will call J.D., is a 22 year old man from an indigenous Quechua culture in Ecuador. He came to the United States to join his brother, who had emigrated nine years earlier seeking asylum. J.D. was brought into the clinic by his brother. He had already seen a private physician to diagnose a large lump which eventually cultured out as M. tuberculosis *of his lymph node. Having been in the United States for many years, the brother had attended college and was relatively acculturated to life in the United States. He spoke English, Spanish, and Quechua, the native language of the patient, J.D.*

Communication Decisions

J.D. was polite, reserved, and concerned as the need for 4-drug treatment was explained with his brother interpreting. J.D.'s Spanish seemed good, but his home language was a dialect of Quechua understood only by people from his region of Ecuador. I contacted the local University in search of an interpreter, but had no luck. J.D.'s brother informed me that in the nine years he had been in the United States, he had not been able to find an interpreter who spoke Quechua. I then concluded that utilizing professional interpreter in the patient's native language was not an option. Initially, it seemed J.D. and his brother had a good relationship, so I used the brother frequently as interpreter in his home language. He was also a good cultural interpreter for me. He explained the multitude of misunderstandings that were possible given the vast cultural differences between J.D. and his medical providers. He spoke of J.D.'s distrust of Western medicine. Back in his native community, J.D. was an assistant to his grandmother, an herbal healer. He also spoke of class and cultural consciousness of oppression of indigenous people and the rich versus poor dichotomy in Ecuador. This was also a big part of J.D.'s distrust of Western ways.

The two lessons I learned from working with this patient are (1) to always keep in mind the risks of using family members as interpreters and (2) to be cognizant of the patience, effort and open mindedness that is needed by all providers in establishing the trust necessary for the patient to complete treatment.

First Meeting

When I was given J.D.'s case, I tried not to have any expectations. I had been a district public health nurse for ten years, so I tried to go in with an open mind.

We arranged for the first DOT visit on neutral ground. J.D. did not want me to come to his home. His brother, unfortunately, was not available for the visit. Since I speak Spanish, it was decided that we would use Spanish to communicate. J.D. never showed for that first appointment. I found out later that he was indeed there at our planned meeting place, but had wanted to observe me from afar before deciding to

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actually show up for a meeting. We set up another meeting in the same place, and after some prodding from his brother, J.D. met with me at the time and place we had chosen. During the meeting J.D. appeared respectful and quiet and seemed to be taking in everything I was saying. I acknowledged that he may have a different understanding of his condition and expressed appreciation for letting me explain our point of view on his care and treatment. I had all of his medication with me, so I explained how to take it. I wasn't sure of what he thought about what I was telling him. Although he did agree to take the medicine, I left our one-hour meeting feeling uncertain.

Treatment Challenges

Shortly after J.D. started his treatment regimen, he began experiencing side effects from the medicine. During our weekly visits, he described dizziness, headaches, and photosensitivity. Because of this, his medical appointments became more frequent. Since a translator in his native language could not be located, professional Spanish interpreters were used for the medical appointments with physicians. Despite this, misunderstandings and mistrust were common, and had to be constantly assessed. The Spanish speaking interpreters were as culturally different from J.D. as the medical providers. Some of J.D.'s comments indicated that he associated many of the interpreters with another class of people, who were closer to "oppressors." This may be due in part to the fact that in his home village, people who were considered wealthy spoke Spanish as opposed to Quechua. Needless to say, this made his medical appointments challenging. Because of the many side effects he was experiencing, J.D. became ambivalent about his treatment. He knew that his grandmother would have treated him with a poultice. He was very concerned about his health, but also concerned about what the medicines were doing to him. It was during this time that the relationship between J.D. and his brother (over unrelated issues) became highly stressed, and I no longer had the J.D.'s permission to occasionally utilize his brother's assistance.

Since I had the advantage of persistence and time to establish a relationship, a level of trust did eventually develop between J.D. and me. I helped him get a driver's license and advised him on many matters unrelated to the TB treatment.

J.D.'s physician felt challenged by the ongoing complaints of side effects and reluctance to continue treatment. He realized that since this was not pulmonary TB and that J.D. was here as a legal immigrant, there were no legal mechanisms to enforce adherence. J.D. held the "power" to

reject treatment completely. J.D. was becoming increasingly reluctant to continue treatment, and began missing our weekly visits. When this happened, I went to his place of employment. This upset J.D. but it also communicated to him that I was not going to simply go away. I explained to him that we had to work this out, and that I understood he was at the end of his rope, but we simply had to work this out. The physician who worked with J.D. demonstrated much patience and willingness to evaluate every complaint. He allowed visits with other consultants (allergists), and experimented with discontinuing various medications in his regimen, until, after 3 months of intermittent adherence, a medication combination that was both approved and tolerated was found. In this process, trust was established with the provider, and J.D. completed his treatment.

Lessons Learned

The two lessons I learned from working with this patient are (1) to always keep in mind the risks of using family members as interpreters and (2) to be cognizant of the patience, effort, and open mindedness that is needed by all providers in establishing the trust necessary for the patient to complete treatment. Throughout his treatment J.D. was concerned about his health and struggled with aligning his interpretation of his health/illness with the ideas pushed so insistently by the public health and medical system. Ultimately, it was this trust that allowed J.D. to consider the possibility that we might be right.

Quick Tip:

Boil it Down to the Basics

Note: While the following information can serve as a helpful starting point, local programs are encouraged to partner with their Regional Treatment and Medical Consultation Centers for guidance and assistance in field testing materials, an important step in the materials development process.

A big budget and a directive from the CEO is not necessary if you're trying to find a tool to communicate with non-English-speaking patients. In fact, the solution can be as simple as printed handouts that you can give to patients.

Helen Osborne, principal of Health Literacy Consulting at www.healthliteracy.com, developed The Linguistic Project while she was working as an occupational therapist for Carney Hospital in Boston. The project was developed in cooperation with **Ann Galvani**, an English as a Second Language (ESL) teacher in the Natick, MA, public school system. The steps they took to develop their written materials can be adapted to situation where verbal communication isn't key to patient interaction:

- Take a typical patient encounter and break all the necessary communication down into its most basic components. For example, in the case of an assessment, start with the greeting and work your way through a series of multiple-choice questions that will help focus in on the patient's complaint or problem.
- Write the outline of the patient encounter down using simplified terms. It is important that people without a medical background can understand information and/or questions in the document.
- Translate the simplified medical information or assessment into several languages. Osborne drew on students in Galvani's ESL program to translate her materials into their native tongues. Other possible sources include in-house translators or multi-lingual media staff.
- Get the in-house translators and media officers to review the translated material.
- Collect the various versions in loose-leaf binders, with the English document on top. Make the binder readily available to staff for use during patient encounters.

To learn more:

- **National Council on Interpreting in Healthcare http://www.ncihc.org/**

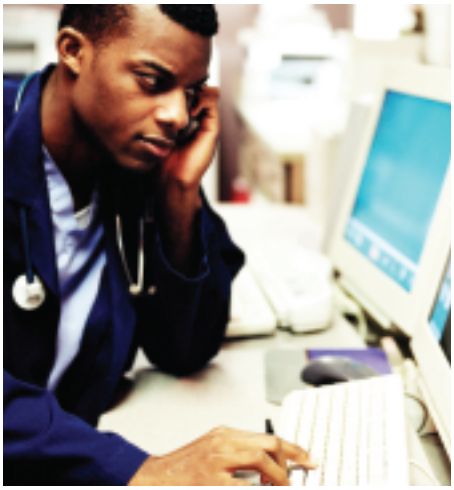
  This website covers a wide range of interpreting information and resources, including an annotated bibliography and a sample assessment of interpreter qualifications

- **Refugee and Immigrant Health: A Handbook for Health Professionals**

  Cambridge University Press 2004 *Charles Kemp*, Louise Herrington School of Nursing and *Lance Rasbridge*, Refugee Services of North Texas, President, together share their 45 years of experience working with refugees and immigrants. Contains a broad overview of more than 30 cultures as well as cultural aspects of health beliefs and practices and religious traditions.

- **Refugee and Immigrant Health (on the web) http://www3.baylor.edu/~Charles_Kemp/refugees.htm**

  A website created by the above mentioned authors, Charles Kemp and Lance Rasbridge. Contains information for health professionals and others about issues, problems, and answers in refugee and immigrant health.



Excerpts from:

Health needs of asylum seekers and refugees

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Michael Peel,
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People who are seeking asylum are not a homogeneous population. Coming from different countries and cultures, they have had, in their own and other countries, a wide range of experiences that may affect their health and nutritional state. In the . . . they face the effects of poverty, dependence, and lack of cohesive social support. All these factors undermine both physical and mental health. Additionally, racial discrimination can result in inequalities in health and have an impact on opportunities in and quality of life.

Refugees' experiences also shape their acceptance and expectations of health care . . . Those from countries with no well developed primary healthcare system may expect hospital referral for conditions that . . . are treated in primary care. This can lead to disappointment for refugees and irritation for health workers, who may also feel overwhelmed by the many and varying needs of asylum seekers, some of which are non-medical but nevertheless affect health. Addressing even a few of these needs may be of considerable benefit.

Previous studies in the . . . have found that one in six refugees has a physical health problem severe enough to affect their life and two thirds have experienced anxiety or depression. Disentangling the web of history, symptoms—which may be minimized or exaggerated for a range of reasons—and current coping mechanisms requires patience and often several sessions. Medication should be as simple as possible.

Many refugees wish to tell their story, which in itself may be therapeutic, but it should not be assumed that people must go through this in order to recover, as some find it extremely distressing. Every culture has its own frameworks for mental health and for seeking help in a crisis. Mozambican refugees describe forgetting as their usual cultural means of coping with difficulties. Ethiopians call this "active forgetting."

Communication

It is important for the services of a trained advocate or interpreter to be available unless patient and health worker speak the same language. Refugees may bring a family member or friend to interpret. Though this may help in obtaining background information, it may result in inaccurate interpreting and also make it difficult to discuss sensitive issues such as sexual health, gynecological problems, sexual violation, domestic violence, or torture. Using children to interpret may place inappropriate responsibilities on them.

Using the same interpreter for all consultations can help the development of trust, but exiled communities may polarize into groups reflecting conflicts in the home countries and not every interpreter will be universally trusted. Interpreters and advocates can provide valuable information for health workers on cultural and other relevant issues. Telephone interpreting can be useful when there are no local interpreters. Also, health workers may need training in working with interpreters.

Information on health

Information about health services needs to be in relevant languages, and some culturally appropriate examples are available covering general access to services (see "useful information"). Some areas have produced leaflets describing local services, but not all refugees are literate, particularly women. Somali culture, for instance, focuses more on oral communication—written Somali dates only from 1972 (N Dirie, personal communication, 2000) and story telling is an important way of disseminating information which has been used in health promotion. Health advocates and refugee community organizations are important in increasing awareness about health. Smoking, for example, is a problem it may be useful to address, as it tends to be high in some groups of refugee men (P Le Feuvre, S Montgomery, personal communication, 2000).

Women

Displacement is difficult for all refugees, but women are often the most seriously affected. They are vulnerable to physical assault, sexual harassment, and rape, and their experiences and fears have tended not to be taken seriously. As refugees,

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they may have to take on new roles and responsibilities, including being heads of disrupted households; they may also have to assume responsibility within the community for education and cultural cohesion, two of the most critical factors for coping, particularly early on, yet this is often not acknowledged. Training and employment programs are almost always targeted at men, leaving women in a weak position to care for themselves and for their families. Where a man is present, stress may make him unable to fulfill his family responsibilities. Divorce and serial marriage are common in communities living under pressure, which may leave women with sole responsibility for the children and with overwhelming domestic responsibilities.

The needs of women may not be identified, especially in cultures where the man is traditionally the spokesperson. Women are less likely to speak English or to be literate, but it is important to speak to them directly, using an independent interpreter rather than a family member. They are more likely than men to report poor health and depression. They may be lonely and isolated but often welcome the opportunity to belong to a group, where they may benefit from the contact and support.

Children

Children may be living in a fragmented family, be with unfamiliar carers, or have arrived alone. They may have experienced violence or torture themselves or have witnessed atrocities; some may have been abducted to become child soldiers and forced to commit violent acts themselves. They may have developmental difficulties, seeming to be mature beyond their years and in a caring role with their parents yet be immature in other situations such as school. They may show anxiety, nightmares, withdrawal, or hyperactivity but few need psychiatric treatment. Support for children needs to be multifaceted, aiming to provide as normal a life as possible, imparting a sense of security, promoting education and self-esteem. It is also important to support parents, as they may be facing difficulties themselves. In some areas, health visitors are taking a leading role in working with refugee families, extending their caseloads to include families with children over 5 years of age.

Conclusions

The basic health needs of asylum seekers and refugees are broadly similar to those of the host population, although previous poor access to health care may mean that many conditions have been untreated. Symptoms of psychological distress are common but do not necessarily signify mental illness. Many refugees experience difficulties in expressing health needs and in accessing health care. Poverty and social exclusion have a negative impact on health. Initially, refugees will need help to make contact with health and social support agencies. Professional interpreters are essential.

Time, patience, and a welcoming approach will break down many barriers, but some refugees have problems that need specialist help and support for which there are few resources . . . It is crucial that these resources are developed before large numbers of asylum seekers are dispersed.

Summary Points

- Asylum seekers and refugees are not a homogeneous group of people, and have differing experiences and expectations of health and of health care
- Symptoms of psychological distress are common, but do not necessarily signify mental illness
- Trained interpreters or advocates, rather than family members or friends, should be used wherever possible if language is not shared
- Community organizations provide invaluable support and can reduce the isolation experienced by so many refugees
- Particular difficulties which face women are often not acknowledged
- Support for children, especially unaccompanied minors, needs to be multifaceted, aiming to provide as normal a life as possible

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1. Did you find this newsletter easy to read? ❑ yes ❑ no

   Why?_____

2. Was the newsletter's length: ❑ too long ❑ too short ❑ just right

3. Will you apply anything from this newsletter to your current practice? ❑ yes ❑ no
   If yes, what specifically _____
   _____
   _____

4. If continuing education contact hours/credits were awarded for future newsletters, would you apply for them? ❑ yes ❑ no
   If yes, what type of contact hours_____

5. What topics would you like to see in future newsletters:
   _____
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Would you be willing to contribute a case study or article? If so, please provide your contact information. Please fax this page to 973-972-1064. Thank you.

Many photos in this newsletter are courtesy of the Stop TB image library at: http://stoptblpipserver.com/

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