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Study: Communicating Torture and War Experiences with Primary Care Providers

Refugees' perspectives on barriers to communication
about trauma histories in primary care

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Abstract

Objective: This study explores refugees' perspectives regarding the nature of communication barriers that impede the exploration of trauma histories in primary care.

Method: Brief interviews were conducted with 53 refugee patients in a suburban primary care clinic in the U.S. Midwest. Participants were asked if they or their doctors had initiated conversations about the impact of political conflict in their home countries. Qualitative data analysis was guided by grounded theory. Peer debriefings of refugee healthcare professionals were incorporated into the analysis.

Results: Two thirds of refugee patients reported that they never shared how they were affected by political conflict with their doctors and that their doctors never asked them about it. Most refugees stated that they would like to learn more about the impact of trauma on their health and to discuss their experiences with their doctors.

Conclusion: Refugees are hesitant to initiate conversations with physicians due to cultural norms requiring deference to the doctor's authority. They also lack knowledge about how trauma affects health. Physicians should be educated to inquire directly about trauma histories with refugee patients. Refugees can benefit from education about the effects of trauma on health and about the collaborative nature of the doctor-patient relationship.

Keywords: Cross-cultural communication, Doctor-patient relationship, War trauma, Refugee

Introduction

A high percentage of refugees seeking health care in primary care clinics are survivors of war trauma or torture.¹⁻³ Despite recommendations that medical professionals consider trauma histories as central to their clinical practice in primary care, doctors often remain unaware of refugees' trauma histories and associated health effects.^{3,4} Physicians tend to focus on the physical complaints of refugees without reference to emotional well-being and the socio-political context of those symptoms. Although recent studies have focused on improving cross-cultural communication between doctors and patients, few studies have focused on the difficulties inherent in explorations of trauma histories in a primary care clinic. ⁵⁻⁷

The United Nations High Commission for Refugees reports an estimated 15.2 million refugees worldwide.⁸ Refugees, by definition, are fleeing their countries due to a well founded fear of being persecuted "for reasons of race, religion, nationality, membership in a particular social group, or political opinion."⁹ Historical estimates of the percentage of refugees who endure the trauma of torture have ranged between 5 and 35%.¹⁰ Studies of more recent waves of refugees from Somalia and Ethiopia have indicated torture prevalence rates as high as 69%.¹¹ Liberian refugees have reported that the vast majority of their community has experienced direct exposure to severe violence.¹²

The aftermath of witnessing and surviving horrific and violent war atrocities leaves many refugees with significant symptoms of psychological distress including posttraumatic stress disorder (PTSD) and major depression. A meta-analysis of 181 studies with over 80,000 refugees found that the strongest factor associated with PTSD was torture followed by cumulative exposure to potentially traumatic events.¹³ An analysis of 160 samples of disaster victims concluded similarly that mass violence contributes to posttraumatic stress disorder more than any other type of disaster, leaving 67% of victims severely impaired.¹⁴ Survivors assessed at The Center for Victims of Torture in Minnesota report rates of posttraumatic stress disorder (PTSD) as high as 88% and depression among 74% of patients.¹⁵ A ten year follow up study of survivors who endure torture indicates that this emotional distress is long lasting and best predicted by physical complaints recorded at baseline.¹⁶

For many refugees, the initial primary care visit may be the first opportunity to detect traumatic experiences and their associated psychological and physical symptoms. Such patients may present with varied and complex symptoms including headaches, abdominal pains, sleep difficulties, traumatic brain injury, body aches and pains, psychosomatic illness, depression, anxiety, posttraumatic stress disorder, and injuries to eyes, ears and mouth.¹⁷ In response to the extreme stress of war, refugees may also struggle with substance use and domestic violence.¹⁷⁻²¹ Communication about trauma histories in the primary care visit is crucial for proper identification of refugees in need of further mental health assessment and treatment. Studies of the doctor-patient relationship suggest that language differences, acculturation process, and cultural beliefs about health care and mental health pose significant barriers to successful communication about mental health symptoms.^{22,23} Researchers have suggested further that physicians may feel uncomfortable asking refugees about their histories of trauma

and unknowingly erect barriers to hearing survivors' stories.⁴ Physicians have also experienced greater difficulty with cross cultural communication when interpreters are needed.²⁴ Refugees themselves have identified a lack of understanding of mental health conditions as a cultural barrier to accessing mental health care when it is needed.²² This brief interview study explores refugees' perspectives regarding the nature of communication barriers that impede the exploration of symptoms of war trauma in primary care.

Methods

Participant Recruitment

Participants were recruited through fliers posted in the waiting area of a low income suburban primary care clinic in Minnesota. Research staff also generally announced to people arriving at the clinic that there was a survey being conducted on immigrant health. To be eligible for participation, participants had to be at least 18 years of age and an immigrant. Prospective participants who expressed interest in the research were informed that the study would involve a 15 minute, confidential interview about health communication between immigrants and providers, as well as selected demographic questions. The interviews were designed to be brief so patients could complete them while waiting for regularly scheduled appointments. Participants were offered an \$8.00 supermarket gift card in appreciation for completing the interviews. Informed consent was obtained from all participants prior to beginning any study activities. The study was approved by the Institutional Review Board of the clinic.

Data Collection

Interviews were conducted in a private section of the clinic waiting area. Participants were asked to provide the following demographic data: country of origin, age, employment status, number of dependents (adults and children), number of clinic visits in the past 12 months and general health concerns. The remaining five questions asked participants: (1) Have you ever brought up with a doctor the ways that you have been affected by the political conflict in your home country? (2) Has your doctor ever asked you about the political conflict in your home country and the ways you have been affected by it? (3) What prevents you from talking to your doctor about it? (4) Do you want to talk to your doctor about it? (5) Are you interested in learning more about the impact of stress and trauma on your health?

Data Analysis

Interviewers took detailed notes during all interviews and registered verbatim as much as possible what participants said. Responses to demographic questions were summarized. Means and ranges were calculated for reports of the number of dependents. To analyze responses to the interview questions, the content analysis followed the qualitative method of constant comparison described in grounded theory.²⁵ The investigators first read the interview notes independently, without consultation, in their entirety to get a sense of the whole. They then compiled the yes/no responses and generated a complete listing of the array of reasons offered as explanation per response. Next, the investigators identified descriptive themes and sub-themes for each question, and then met to come to agreement on the coding of themes thus far. Each investigator then reviewed the original transcripts again in their

entirety to gather support for each theme, sub-themes and supporting quotations, checking the consistency and accuracy of application of coding through constant comparison. As part of the overall process, every response was accounted for and made part of the coded data set, including counter examples. Finally, themes and sub-themes relating to all questions were re-examined for frequency and content of response.

As a check on the validity of themes developed and to provide explanation of themes, peer debriefings were conducted with health professionals from Liberia, the largest immigrant group. Each shared comments on the socio-cultural context of mental health treatment in Liberia. These key informant interviews were summarized. Although this small sample did not permit analysis of significant differences associated with demographic factors, we did examine the data for any potential patterns in responses related to gender or national origin.

Results

Participant demographics

Fifty-three patients participated in the study. Three participants indicated in their interviews that the subject of war trauma was not relevant to their lives. The responses of these participants (two Africans and one Latin American) were excluded from the analysis. As indicated in Table 1, 64% of participants interviewed were female; 74% of all interviewed were Liberian. The other participants came from Laos (3), Thailand, Vietnam, Cambodia, Nigeria, Kenya, Ethiopia, Ivory Coast, Bosnia, Peru and Colombia. Participants reported having 3-4 people (adults and children) under their care. Most (86%) held full time employment. Nearly all (88%) lived in the suburb of the clinic or immediately adjacent ones.

Visits and Stated Health Concerns

Forty-six percent (23 participants) reported a frequency of 1-2 clinic visits per year; and 50% (25 participants) reported 3-6 visits per year. Five participants (10%) reported 7-12 visits per year (Table 1). When asked about health concerns that brought them to the clinic, participants named biomedical problems such as diabetes, hypertension, fibroids, asthma (including children's), digestive problems, acute illnesses such as colds or flu and annual physicals and prenatal care. Ten noted chronic pain (especially back, but also knee, leg, headaches); of these two mentioned not knowing the origin of these pains. Just four participants (three female and one male) related their clinic visits to somatic and psychological issues such as headaches, anxiety, depression, stomach aches, trouble sleeping. One woman responded to the question of whether she had ever initiated the subject of how she had been affected by war with her doctor, saying "Yes, because of my anxiety, I had to bring it up." (participant 1). Another woman said in response to the question about whether she would want to talk about war experiences with her doctor saying, "If any doctor asked me I would say my father is dead." She went on to describe repercussions of the war on her family back in Liberia, saying "Every time I call [family at home in Liberia], they say 'no food' and 'how to pay rent.' When my family says 'no food,' I get a terrible headache. You be depressed too. ... I can't comprehend my studies [when I get a headache]." (participant 2).

Key findings on refugee-physician communications about war trauma

Doctors and patients do not initiate conversation about war trauma

More than two-thirds (68%, or 34 participants) reported that they had never initiated conversation with their doctors about the ways they had been affected by the political conflict and violence in their home country. Among the 13 participants who had raised the subject with their doctor, half reported that they had a direct discussion of war-related anxieties. Two indicated the conversation had been “brief” or “on a casual note.” Similarly, about two-thirds of patients (64%, or 32 participants) reported that no doctor had ever asked them about the political conflict in their country or the ways they had been affected by it. Some participants gave clear negative responses:

“No, no one has asked me about this.” (participant 3)

“No, neither my doctor nor my baby’s doctor has asked about the situation.” (participant 4)

“She has never asked me. We strictly do medical things.” (participant 5)

“Though they know me to be a refugee, they don’t ask me.” (participant 6)

Among the affirmative responses (from 13 participants), about half suggested a cursory exchange, similar to those who said doctors had not raised the subject.

“Some people want to know where you’re from and how things are going in the United States.” (participant 7)

“They have asked where I’m from but nothing about my experiences of life in [country].” (participant 8)

“(S)he only asks me who I go to see to explain my problems. I don’t tell anyone. I just tell God.” (participant 9)

There were, however, six participants who indicated that the doctor had clearly and directly addressed the issue of mental health problems stemming from war trauma.

“When I came here they asked me about my history and what concerns me. I was able to talk about the situation and the family members that were still over in Liberia.” (participant 10)

“She [the doctor] knew about the situation in my country and when I came she asked me about the situation and how I was affected by it.” (participant 11)

“When I [go to x clinic], they ask me about my experiences. My mom was killed because of the war.” (participant 12)

A Liberian woman working full time and providing for six people reported having been asked by her doctor about her experiences in Liberia.

“because of the war we went through a lot. We left the country and went to live in a refugee camp. There were no medications or health care. Since coming here we have been going to the doctors and we tell them about our experiences because they ask....yes, my family and I are still going through this. Because we were here we applied for asylum and some of us were denied. (participant 13)

Another Liberian woman recalled

“years ago when I first came, a doctor became very concerned about me. [...] My blood pressure was very high, so the doctor asked the necessary questions. (S)he asked where I was from, found out my family was missing [for 3 years], after that (s)he was very concerned, about other than health.” (participant 27)

A couple of participants indicated that they did not respond directly to their physicians' questions. “She asked me questions about it. I told her I was not feeling good in this country because of all the expenses but I haven't really talked to her.” (participant 14)

“When he saw the scar on my [part of body] he asked me what happened and how I got it. We didn't go into detail about it and I didn't talk of other things that happened in the war.” (participant 15)

Barriers to talking about war trauma with physicians

Participants reported multiple barriers to taking the initiative to talk about war trauma with their doctor. Three of the most common were these: 1) Participants stated that they were not asked about their histories of war trauma and they felt that it was appropriate to talk about this topic only if the doctors initiated the discussion; 2) Participants did not consider the impact of war on them as a health related issue or as a relevant topic for clinic visits; and 3) Participants did not want to raise bad memories.

Table 2 presents frequencies associated with the ideas participants offered as explanation for not talking to their doctors about the ways they have been affected by political conflict or war in their home countries. Analysis of these responses in relation to the interview overall suggested that a larger number of participants (36% or 18 participants) did not feel comfortable raising the subject with a doctor, but would most likely respond to a doctor's initiative.

“Because I was not asked about the situation I did not talk to my doctor. I would be willing to talk about it if I was asked.” (participant 16)

“No [nothing prevents me], it's just nobody brought it up so I'm keeping quiet.” (participant 17)

“I feel I should be asked before I bring anything up. It's hard to just start talking about these things to your doctor.” (participant 14)

"I would explain what I saw and what really happened, things that affect me and my family during the war. [I] haven't been asked about." (participant 18)

Several participants (10, including 7 males) did not view the impact of war as a health concern.

"When I come to the clinic we only talk about my health issues." (participant 7)

"When I went in to the doctor that was not the purpose of my visit. It was not intended for discussion so I didn't talk about it." (participant 15)

"The conversation never came up. He would only ask me about my health concerns. Nothing really prevents me except he comes in and out and he tells me to do certain things. He seems busy and preoccupied. We mostly talk about lab results. The interpreter always seems busy too." (participant 19)

"Sometimes it's not the subject. You're seen for a health issue, they give you a prescription and you're out the door." (participant 20)

There was an evident gender divide in many responses, suggesting that male participants did not see mental health concerns as relevant to clinic visits. By contrast, the female responses suggested a reticence to initiating the discussion with a doctor, but otherwise receptivity. In response to this question, some participants emphasized the doctor's lack of time.

"Some don't want to know the story and they don't have time to listen." (participant 21)

With one exception, Liberian men did not share war experiences and were more skeptical about the benefits of discussing how the war has affected them with their doctors than women were.

"Yes, if they asked me I would tell. I don't see the benefit but sometimes they like to know your mind." (participant 22)

Another Liberian man, who said he had never discussed these issues with a doctor, indicated more openness, saying [if the topic arose with a doctor],

"I should be very truthful to him about my situation because my health is the most important thing. When I come I'm mostly concerned about my health and second comes this topic about my country." (participant 23)

Patients are interested in communicating trauma histories with physicians

Seventy-four percent of participants (n=37) said that they want to talk to their doctors about war trauma. It is important to note that almost half, or 18 of the 37 affirmative responses (49%), were prefaced by an "if." Several stated that they would want to talk if the doctor asked (8 responses) or if it was, in fact, helpful to their health. One participant said she would talk if

the doctor had the time; another would talk if (s)he had gotten to know the doctor; a third would talk, but imagined that the doctor wouldn't be interested. Several others said they would talk about it if it was necessary and helpful to their health (7 responses). Some of these responses suggested reservations or skepticism.

"If it is an issue that I need to talk to him about, then I would want to talk to him about it."
(participant 24)

"If it will help my health, then I feel it is important to communicate with my provider the things that happened in Liberia." (participant 10)

"The doctor asked and I explained. It's kind of hard to do but once you do it, it really helps."
(participant 25)

Six participants who said they were not interested in talking about war trauma with their doctor reiterated their desire to forget the past and move on.

"When you reflect back, it's very hard because of stuff that happened. When you go without food for days and you live on leaves... When I talk about it, I go back. I don't really like to think about it." (participant 26)

Two participants noted that they do speak to their doctors about war related stress. Four participants specified that they wanted to talk to their doctor to determine whether their anxiety or health issues were related to psychological stress and five stated they wanted to do so in order to get well or improve their health.

"Yes, because I want to get well. If I don't bring it up, then how will they help me?" (participant 1)

Two noted that they can and do speak to their doctors about such issues.

Refugee patients are interested in learning about the impact of trauma on health

Eighty percent of participants (41 participants) expressed interest in learning more about the impact of stress and trauma on their health. Most who responded with interest spent time going through a brochure on symptoms of stress and trauma together with research staff. Study staff were struck by how quick some were to raise memories even in the context of a brief interview. Thus a woman said in response to the question about communication barriers with doctors. "The subject never came up and I'm shy to talk about it. I walked for one week straight and saw some people killed in front of me." While going through the brochure, a 26 year old Liberian woman (participant 27) who had been in the U.S. nine years said she has migraines, trouble sleeping and back pains. She also said she saw her mother, father, brother and sister killed.

Perspectives from Liberian healthcare professionals

The three Liberian healthcare professionals interviewed pointed out that people in Liberia, especially in rural areas, only go to see a doctor once they are very sick. Having finally done so, they are focused on that issue alone. The healthcare professionals suggested other potential reasons why Liberians don't initiate discussions of their mental health concerns during clinic visits.

"There needs to be a relationship before you can tell your story. Doctors in America ask a list of questions. Patients have a difficult time asking questions because there seems to be an agenda...very few people would volunteer information because they wouldn't want to look like they were challenging authority." (Liberian doctor)

"Doctors are highly respected in African culture. Because of this, patients will usually wait to be addressed and asked questions of by their doctors. Lay people will typically wait to be asked and give simple 'yes/no' answers...if [Liberians] think you're just asking about it for interest sake, they may not get into their stories." (Liberian nurse)

Finally, another Liberian nurse offered another explanation for why Liberian men may not talk about their war related stress.

"Liberian men don't want to show emotion and they may try to avoid this by not talking about the war."

Discussion

The results of brief interviews held with 50 patients at a U.S. Midwestern primary care clinic suggest that many refugees are unlikely to volunteer their trauma histories to their doctors. The interviews indicated two key communication barriers from the perspective of participants: 1) the doctor did not raise the topic, and 2) a sense that the discussion of personal experiences and related mental health problems were not appropriate for a primary care visit. The next two most often noted barriers were reluctance to remember the past and a sense that the doctor did not have the time. While most have not spoken to their doctors about their war experiences, the majority expressed a willingness to discuss them with their doctors to improve their health.

Since the refugees in this study spoke English, most did not indicate that language was a barrier to communication. Participants cited two important cultural barriers: 1) the lack of knowledge that emotional distress from the war could be a health problem, and 2) a belief that they should defer to their doctor's authority and should not be the ones to initiate a discussion about their traumatic experiences. Several participants did not appear to define or understand healthcare as extending to mental health. Most participants appeared to believe that it was not their place to initiate such a discussion with their primary care provider, but would respond if asked or would respond if it truly would help their health.

Strengths and Limitations of this study

This is the first study to examine communication barriers related to sharing trauma histories in primary care from the perspective of refugees. Since most participants in this study are Liberians, it is not possible to generalize these findings to all refugee populations. Although the sample is too small to make any claims of significant differences, the data appears to suggest that these barriers may fall along gender lines. Most male participants seemed skeptical of the benefit of discussing the psychological impact of war with their providers while female refugees tended to be cautiously open to the possibility of doing so if it would benefit their health. Despite the many reservations expressed about communicating with their providers about war trauma, the majority of participants, male and female, said they would do so to receive the help they need for their health. Many immediately expressed interest in learning about the impact of trauma on their health.

Conclusions and Recommendations

Most refugees did not share their trauma histories with their doctors for reasons that reflected their lack of knowledge about how trauma affects health as well as cultural assumptions about the nature of the doctor-patient relationship. More research needs to be done with diverse refugee populations to understand culture specific barriers to communication about trauma in primary care. Physicians also need to be included in research that explores their own difficulties communicating about trauma cross-culturally. Research that focuses on the development of short inventories to aid physicians in explorations of trauma across cultures may be helpful in practice with refugees in a primary care setting.⁷

This study suggests practice recommendations for educating physicians as well as refugee patients. Physicians should be encouraged to inquire directly about the trauma histories of refugees and to provide education about the potential impact of that trauma on long-term health outcomes. Recent studies of torture survivors in primary care have recommended a two step question format that is effective at eliciting torture and war trauma histories. Patients are asked, "Were you ever harmed or threatened by the following: government, police, military or rebel soldiers?" and "Some people in your situation have experienced torture. Has that ever happened to you or your family?"¹⁷ These few simple questions have been effective at identifying torture and war trauma survivors in need of further assessment for the somatic and psychological symptoms associated with trauma. Some resident training programs have begun to incorporate curriculum related to assessing war trauma and torture survivors with promising results.²⁶

Refugees themselves also need to be educated about the effects of trauma on health and mental health. Normalizing symptoms of trauma can bring great relief to refugees who may think they are "going crazy" when they are simply struggling with symptoms that are treatable through appropriate mental health care. Refugee patients can also benefit by being educated about the collaborative nature of the doctor-patient relationship. In many countries, doctors have historically been complicit in the practice of torture and they may be feared by patients who are uneducated about professional practice and civil rights in the Western democracies like the United States.²⁷ Refugees should be empowered to express their health and mental

health related concerns directly, especially when they are fleeing countries with oppressive regimes where their voices have been silenced by officials in positions of authority.

Disclosure

I confirm all patient/personal identifies have been removed or disguised so the patient/persons described are not identifiable and cannot be identified through the details of the story.

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