

Chronic Disease Care Experiences of Meshketian Turkish Refugees

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ABSTRACT

After many decades of displacement, violence, and discrimination, the Meshketian Turks gained refugee status and were allowed to resettle in the United States. About twenty to twenty five families were placed in Charlottesville, Virginia. Many of the adult refugees suffering from hypertension, hyperlipidemia, and type 2 diabetes received treatment from the International Family Medicine Clinic (IFMC) at the University of Virginia. A number of health care providers reported that some refugees were not complying with the recommendations of their doctors (medication regimens, follow up appointments, and lifestyle modifications). In order to ascertain patients' understanding of their medical conditions and to improve their care, twelve individual scripted interviews were conducted by a Russian speaking medical student. It was found that Meshketian Turks do not understand the concept of a chronic condition, thus explaining why so many have a difficult time complying with their doctor's recommendations. Furthermore, it was discovered that immigration as well as other stressors significantly impact the health of Meshketian Turks.

INTRODUCTION

A traumatic history and a milieu of social constraints, both in their country of origin and in the United States, shape the medical issues facing Meshketian Turkish refugees living in Charlottesville, Virginia. Their unique narrative and encounters with various cultures have impacted Meshketian Turks' approach to American health care as well as their general beliefs and attitudes toward personal health. The term "Meshketian Turks" refers to a group of Turkish-speaking Muslims who originate from Meskhetia, a region on the Georgian-Turkish border¹. It is unclear whether the people now referred to as Meshketian Turks were originally ethnic Turkish tribes who settled in Meskhetia in the 5th century or ethnic Georgians who converted to Islam and learned to speak Turkish during the Ottoman rule of Meskhetia¹.

While the ethnic origin of Meshketian Turks remains in dispute, according to some sources the group gained its cohesive identity only after its deportation from Meskhetia². In 1944, Meshketian Turks along with a number of other smaller ethnic groups in Meskhetia were charged with collaborating with Nazi Germany; thus they were forcibly deported from Georgia to other

Soviet republics in Central Asia—such as Kazakhstan, Kyrgyzstan, and Uzbekistan^{1,2,3}. Stalin's regime dealt swiftly and brutally with the Turkish speaking Muslims in Meskhetia, confiscating their belongings and placing them in cattle cars for deportation¹. The Meshketian Turks were not given more than a few hours to get ready; thus over the course of 3 days in November of 1944, approximately 100,000 people were forced from their homes and removed to central Asia¹. Many thousands died during the month-long journey¹. One survivor noted: "at each stop they would unload the dead"¹. Once they reached their destination many more died due to hunger and cold¹. Within four years of their deportation, approximately 15-20% of the Meshketian Turkish population had perished¹. Note that a few of the elderly refugees interviewed for this study survived this period.

After their deportation, the Meshketian Turkish population was scattered over several Central Asian Soviet republics^{1,2}. For decades they lived mostly in poverty, branded as "enemies of the people," and often in the midst of hostile local populations^{1,2}. It was in exile that the Meshketian Turks banded together and developed a distinct and separate identity¹.

This study concerns itself with the fate of the refugees who were resettled in Uzbekistan. The next precipitating event in the history of these people was the 1989 Fergana Massacre¹. In June of 1989, ethnic violence broke out in Fergana Valley, Uzbekistan, resulting in the deaths of approximately 100 Meshketian Turks¹. To curb the tension, the Soviet army evacuated 17,000 Meshketian Turks from the area and another 70,000, from other parts of Uzbekistan, left on their own¹. Once again, the population scattered—settling in Azerbaijan, Ukraine, Kyrgyzstan, Kazakhstan, and Russia¹.

Many of the Meshketian Turks who fled Uzbekistan settled in Russia's Krasnodar Region. Soon after their resettlement the Soviet Union collapsed and the Russian Federation was established. The authorities in the Krasnodar region refused to recognize the Meshketian Turks, defying the Russian Federation's Citizenship Law, which granted citizenship to all former Soviet citizens living permanently in Russia³. By denying the Meshketian Turks citizenship, the Krasnodar authorities denied them the right to work, freedom of movement, access to pensions, child benefits, and access to higher education³. Meshketian Turks living in Krasnodar territory could not officially register houses or vehicles purchased; they could not record marriages, deaths, or

births^{1,3}. Those living in the region were harassed by authorities; for example they were “frequently stopped and questioned by police on the pretext of checking identity documents and obstructed in going about their daily business”³. Most importantly for this study, the Meshketian Turks were denied free health care because they were not recognized as Russian citizens¹. To receive health care, Meshketian Turks had to pay out-of-pocket, a luxury many could not afford¹.

After over seven decades of displacements, ethnic violence, and State-sponsored discrimination, the Meshketian Turks found themselves “a perpetually stateless people”¹. In 2004, the United States government granted refugee status to the Meshketian Turks living in the Krasnodar territory¹. As of June of 2006, about 9,000 Meshketian Turks from Krasnodar had arrived in the United States and 3,000 more are scheduled to arrive by the end of 2007¹. The International Rescue Committee (IRC) resettled about 20-25 families in Charlottesville, Virginia. All of these refugees received initial medical care at the International Family Medicine Clinic (IFMC) and many of them still receive care there. The clinic operates in the Department of Family Medicine, University of Virginia Health System and it caters toward all refugees arriving in Charlottesville, Virginia.

While the IFMC specializes in medical care of refugees, it does not presume that all ethnic groups require the same type of attention. Caring for the Meshketian Turks from Krasnodar poses its own unique problems due to their distinctive history. Yet almost nothing has been written about the medical care of these refugees; for instance, an Ovid Medline search yields no hits on the term “Meshketian Turks” or its several spelling variations. One purpose of this study was to begin to redress the lack of literature addressing the medical problems and care of Meshketian Turks.

While little has been studied about the medical care of Meshketian Turks, a large number of scholarly articles have been written about providing medical care to other refugee populations from the former Soviet Union, particularly Russian Jewish refugees. Because Meshketian Turks were citizens of the Soviet Union and utilized the Soviet health care system, it was presumed that some similarities could be expected between Meshketian Turks and other post-Soviet refugees. To what extent Meshketian Turks were similar to other Soviet refugees could not be determined. Assessing the differences and similarities between Meshketian Turks and other Soviet refugees is another purpose of this study.

The Meshketian Turks that arrived in Charlottesville suffer from many chronic conditions, not unlike the Soviet refugees in other studies⁴ or the post-Soviet

citizens remaining in Russia and other former Soviet republics⁵. According to the CDC report on the Russian Federation, an increase in cardiovascular disease was one of the two major causes of increased Russian mortality both in 1990-94 and in 1999-2000⁶. Furthermore, the World Health Organization calculated cardiovascular disease to be the number one cause of disability in both Russian men and women, earning the highest DALY (Disability Adjusted Life Years) value⁷. Another chronic condition that Russian health care faces is diabetes. In 2000, the Russian Federation was ranked seventh in the world for the number of people (4.6 million) with diabetes⁸. Similarly to the other Soviet ethnic groups, many of the middle aged and elderly Meshketian Turkish patients seen at the IFMC suffer from chronic conditions such as hypertension, hyperlipidemia, and diabetes. In some cases, the refugees were diagnosed and treated in Russia before their arrival in the United States.

The new refugees were seen and evaluated at the IFMC soon after their arrival. Appropriate care and treatment were administered. However, many of the providers found it difficult to care for the Meshketian Turkish refugees, often noting their failure to adhere to recommendations, such as medications, follow-up care, and lifestyle changes. The main purpose of this study was to explore the underlying reasons for these problems. In order to accomplish this task, a one-on-one interview was conducted with adult refugees who suffered from either hypertension, hyperlipidemia, diabetes, or a number of these conditions. The interview questions were designed to assess the patients’ understanding and knowledge of their conditions and treatment prescribed. The patients’ knowledge of preventative care was also tested. Satisfaction with care provided by the IFMC as well as ability to access care and medication were also evaluated by this study. Ultimately the goal of this project was to improve the care that Meshketian Turks and other refugees receive at IFMC.

METHODS AND MATERIALS

The Institutional Review Board for the Social and Behavioral Sciences at the University of Virginia Health System approved this study. All of the subjects in this study were current or previous patients of the International Family Medicine Clinic (IFMC) in the Department of Family Medicine, University of Virginia Health System. They were identified through both physician referrals as well as an IFMC database search. Adult patients of Meshketian Turkish background who were diagnosed with hypertension, hyperlipidemia, or type 2 diabetes mellitus were chosen to be invited to

participate. Twenty-four patients were identified by these criteria and attempts to contact them via phone were made. The recruitment call and the patient interview were both conducted in Russian by a native Russian speaker, thus either the patient had to speak Russian or an adult child had to be available to translate.

The hour-long interviews took place at a date and time convenient for the patient. The interviews were conducted at the International Family Medicine Clinic or, if after clinic hours, in a private classroom at the Claude Moore Health Sciences Library. Both locations allowed for a quiet, confidential setting. Clients were interviewed individually, even if more than one family member was interviewed for the study. Because the population in question has low rates of literacy and is not used to signing forms, written consent forms were thought to be too intimidating. Consent was obtained verbally and tape recorded along with the interview.

A number of scripted questions were asked to assess the patient's understanding of his or her diagnosis, prescribed treatment, compliance with treatment, preventative care measures, and access to care and medications. The interviews were then translated into English and transcribed by the interviewer. No names or identifying information were recorded on the tapes and transcripts. The patients were simply coded by a number. Out of twenty-four eligible subjects, a total of thirteen patients were interviewed. Unfortunately, one interview failed to record on the tape and thus only twelve patients were analyzed for this study. Five other patients were contacted and declined to participate. We were unable to reach six patients. Note that some patients suffered from more than one condition and were interviewed simultaneously about both chronic illnesses.

As an incentive the patients received a twenty-five dollar gift certificate to a local grocery store or pharmacy and were given parking validation for the duration of their interview. Furthermore, patients also received information packets in Russian regarding their particular condition. This research was carried out as part of the Medical Student Summer Research Program and the interviews were conducted in the summer of 2007, between June 29th and July 17th. For the telephone script, consent script, interview questions, and follow-up letter in both English and Russian see appendix 1-4. For the most part the collected data was summarized in a qualitative manner with emphasis on common themes.

RESULTS

A number of general questions were first asked in order to understand the patients participating in this study. All of the subjects were from the Krasnodar territory and moved to Charlottesville either in 2005

(four subjects) or in 2006 (eight subjects). The range of the subjects' ages was from forty-six to eighty-four. Three of the subjects were in their eighties, one in her sixties, four in their fifties, and four in their forties. All of the subjects lived with other family members; ten out of twelve subjects lived in a household that contained three generations (grandparents, parents, and children). The other two subjects lived in nuclear households containing two generations. When posed with the question of how they feel on an ordinary day, almost half of the subjects reported dissatisfaction with their everyday health. The subjects reported nine cases of hypertension, four cases of hyperlipidemia, and four instances of type 2 diabetes. Note that five subjects had more than one condition. Three subjects were suffering from both hypertension and diabetes; two subjects had both hypertension and hyperlipidemia.

Out of the seventeen total conditions suffered by these patients, eleven were diagnosed in the former Soviet Union or Russia and six were found in the United States. Interestingly all nine cases of hypertension were diagnosed in Russia. On the other hand, three out of four diagnoses of hyperlipidemia were made in the States and three out of the four instances of diabetes were discovered in the States. This finding suggests that while hypertension is commonly diagnosed in the former Soviet Union, hyperlipidemia and diabetes are likely to be missed. This is further supported by a study of another Soviet refugee group in which all patients denied ever having their blood cholesterol level checked⁴.

In conducting this study, it became clear that Meshketian Turks lacked a basic understanding of the chronic conditions from which they were suffering. This could be partially attributed to the lack of explanations provided by their Russian physicians. For example, when asked how their condition was explained to them, the refugees' most common response referred to tests being run and medications being prescribed:

“There they don't say anything. I just went to the doctor. He took some tests, prescribed some medications and that's it.” [male patient with diabetes]

“They didn't explain anything. In Uzbekistan they never say the reason...they just check it, measure it, and prescribe medication.” [female patient with hypertension]

“You know, they never explain anything, why and how...they give medications and shots and that's it, you go home.” [female patient with hypertension]

Only one patient correctly attributed her high cholesterol to her diet, but it was unclear whether her knowledge was gained in the States or in Russia, as she

claimed that she had been told about her high cholesterol at one point in Russia, but had forgotten about it by the time she moved to the US. Another patient claimed that her doctor attributed her hypertension to her gallstones. Finally, one patient mentioned that her hypertension was explained by her menopause. The connection between high blood pressure and menstruation and/or menopause was one theme noted in a number of the interviews conducted with female patients. Note for example the following dialogue between one patient and the interviewer:

Patient: “I have high blood pressure because I’m going through menopause. I stopped menstruating after my operation. And menopause is raising my blood pressure.”

Interviewer: “Is this what your Russian or American doctor told you?”

Patient: “I know this myself.”

It was clear from these interviews that Russian doctors failed to explain the chronic conditions with which these patients were burdened and that, as a group, Meshketian Turks know very little about hypertension, hyperlipidemia, and diabetes.

Based on further questioning, it did not appear that American doctors offered a much better explanation regarding these chronic conditions. When asked how their American doctors explained their disease, Meshketian Turks were much more likely to cite the same understanding as above—of doing tests and prescribing drugs. One patient who had been diagnosed with hyperlipidemia in the United States had specifically agreed to be interviewed in hopes of learning more about his condition:

Interview: “And how did the doctor explain this [hyperlipidemia] diagnosis?”

Patient: “He said to eat less fat, to stay away from fattening food.”

Interviewer: “And did he explain why that’s important?”

Patient: “Yes it’s important for me. I don’t know why. I’ve never felt I had this, I don’t know what it is. I want to find out what it is, that’s why I agreed to this interview.”

It is unclear whether the failure of understanding stems from a language gap between Meshketian Turks and American physicians or from the assumptions by American physicians that the Meshketian Turks are already aware of the pathogenesis of these common problems as most Americans are. The interviewer discovered one positive sign: the patients who had been

diagnosed with diabetes were all referred to a diabetes education clinic.

In talking about the difference between Russian treatment and American treatment, the refugees often stated that “for the most part there [in Russia] they give shots, but here they give shots less frequently. For the most part [American doctors] prescribe pills.” This observation is corroborated by a study that observed the prescribing practices of rural primary care physicians in Uzbekistan⁹. The researchers found that on average 57% of the drugs prescribed in these regions were administered by injections⁹. The high rate of drug injections could lead one to believe that Meshketian Turks are mostly unaccustomed to oral medications as a form of long term treatment. One study of Soviet refugees confirmed the above prediction and found that “compliance to medication was challenging...because in Russia, anti-hypertension medications were usually taken once a month and in the form of an injection. They [refugees] find it difficult and inconvenient to take pills daily and indefinitely”¹⁰.

Compliance with a medication regimen varied from person to person. More than half of the patients stated that they follow the prescribed regimen of pills. The most common reason for not taking their medications regularly was that they “felt normal.” For instance, one patient explained:

“My daughter checks my blood pressure. If my head hurts, she comes over, measures it and tells me that I have high blood pressure. Then I take the pills.” [male patient with hypertension]

This conditional compliance with the medication routine illustrates the fact that many Meshketian Turks do not understand the concept of a chronic condition. A number of patients reported that either they or someone in their family owns a blood pressure cuff and that they often use it to ascertain their blood pressure and whether or not they need their medication that day. Moreover, many patients expressed concern over taking too much medicine:

“I take them almost everyday, I should take them three times a day but I don’t. Taking them everyday, constantly, no matter how good they are...I mean they heal one thing, but hurt something else.” [female patient with hyperlipidemia]

Other studies confirmed the existence of this idea in post-Soviet populations that “too much of any medicine can be poisonous”¹¹.

Meshketian Turks reported that they sometimes, but not always, turn to home remedies in order to treat their

condition. The most common example of a home remedy was the use of green tea or green tea with sugar and lemon to treat high blood pressure. One disturbing finding was that two patients believed that smoking cigarettes lowers blood sugar and used this method to partially control their diabetes.

As a number of studies have observed, Russian doctors very rarely prescribe lifestyle modifications such as diet or exercise for chronic conditions^{4, 10, 11, 12}. “Lifestyle modification as a first-line treatment for diabetes and hypertension is unknown. Exercise is not typically recommended, and there is no widespread exercise culture, such as jogging or even walking...Diet tends to be high in salt and fat,” one investigator wrote¹². In this study as well, only three people reported that a change in diet was recommended to them by their Russian doctor and only two people were advised to exercise. Thus it is not surprising that despite the recommendations of their American physicians, a number of Meshketian Turks in our study do not comply with the dietary recommendations and do not exercise on a regular basis. However, more than half reported an attempt to both exercise and to eat a healthy diet. Unfortunately this survey was not designed to ascertain whether the patients’ lifestyles are appropriate for their respective conditions.

The interviewed patients also knew very little about preventative care. Most said they don’t know what kind of lifestyle changes could have prevented their chronic disease. Only two patients provided concrete and accurate suggestions of how their chronic condition could have been prevented. However, when prompted to answer whether diet and exercise specifically could help treat and prevent their illness, seven patients agreed that diet and exercise could in some way be beneficial. It is unclear whether this admission is an accurate statement of the refugees’ beliefs or an attempt to consciously or unconsciously please the interviewer.

As a whole, Meshketian Turks had a very vague notion of what constitutes a healthy diet and how much exercise is appropriate, similarly to their Russian counterparts^{5, 6}. A number mentioned that fruits and vegetables are healthy and that a diet must be low in fat, salt, and fried foods. Many patients said that a healthy diet consists of everything in moderation. Most Meshketian Turks did not know the amount of exercise recommended; only one patient was able to answer accurately that most doctors recommend thirty minutes of exercise a day.

The Meshketian Turks differed from many other Soviet ethnic groups in that they reported a very low incidence of smoking and alcohol consumption^{4, 10, 13}. None of the women interviewed smoked or drank; one of the patients informed the interviewer: “in our culture,

women don’t smoke or drink alcohol.” Of the four men that were interviewed, only one smoked (another quit at the age of forty), though all four drank alcohol on occasion. All of the subjects interviewed agreed that smoking and alcohol negatively affected their health.

In conducting these interviews we hoped to learn about the challenges and barriers Meshketian Turks face in obtaining treatment for their chronic conditions, thus we also asked the subjects questions regarding their access to care and medications. A number of middle-aged patients reported that while working, they could not afford insurance and therefore were now unable to obtain primary care. The patients reported no problems obtaining appointments and were able to call in or have someone else call in to make an appointment with their doctor. Few problems with obtaining medications were reported. In general, the patients were happy with the doctors at the IFMC and the care they provided; many positive comments were recorded.

DISCUSSION AND CONCLUSION

The most significant finding of this study was the extent to which the Meshketian Turks lacked a basic understanding of hypertension, hyperlipidemia, and diabetes. The subjects’ conception of their diagnosis consisted of what they were told to do—what medicine to take and what foods to eat and not to eat. Moreover, in some cases, the patients’ understanding of their condition was simply wrong. For example the subjects tended to draw a connection between having a headache and having high blood pressure; one patient diagnosed with hypertension had a typical comment: “I get a headache, from this I know I have high blood pressure.” Thus it is important that health care providers not assume that patients understand their illnesses, even those patients who have long suffered from their conditions, and even those aspects of an illness that are common knowledge to most Americans.

Furthermore, not only were the specific conditions studied (hypertension, hyperlipidemia, and diabetes) unfamiliar to the refugees, but the entire concept of a chronic disease was foreign. Meshketian Turks in this study equated the concept of feeling ill with being ill and could not appreciate a condition with which they could be diagnosed and not have any noticeable symptoms. For instance, one male patient diagnosed with hyperlipidemia was quizzical:

”They checked us and said that I had this [hyperlipidemia], but I’ve never complained about this...I’ve never felt like this, I’ve never felt bad...I’m not complaining [about feeling sick or ill] or anything, but I’d like to find out whether I have

this or not. Maybe the doctor made a mistake with the diagnosis.”

in Russia, everybody got left behind.” [female patient with hypertension and diabetes]

The Meshketian Turks appear to define health as the “absence of illness” or “the lack of a negative rather than the presence of a positive state,” similar to the views recorded in other studies of post-Soviet citizens^{5, 10}. Thus it is difficult for them to accept daily prescribed treatment regimens without an end-point in sight and a condition which cannot be cured, but only controlled. Many patients worry about the side-effects of too many pills, thus leading to poor compliance: “no matter how good they [the pills] are...they heal one thing, but hurt something else,” explained another hyperlipidemia patient. Thus these refugees, not unlike the other Russian refugees studied are at risk of “complications with the diseases that require self-management”¹⁴.

It is the opinion of the author that poor understanding of these conditions as well as of the entire concept of a chronic disease leads to poor compliance—failure to follow drug regimens, failure to follow up, and failure to engage in lifestyle modifications. Moreover, because patients have little understanding of what caused their illness, they have no concept of preventative care. Thus patient education is a necessary part of any treatment plan, especially for this population.

Another major finding of this study was the extent to which stress was observed in and reported by the subjects. A number of the subjects vented their worries with regard to their medical conditions and medical bills, their lack of insurance, money, and language skills during the course of the interview. Two female patients began crying during the conversation. Undoubtedly, the stress immigrants undergo has been observed in many studies^{12, 15, 16}. One author writes that the “life circumstances associated with immigration include loneliness and depression as well as limited social and financial resources,” implying that it is not uncommon for immigrants to develop psychological issues¹⁶. Another source claims that “many [refugees] have to deal with the psychological burden and guilt of having left behind relatives and friends who still live under dire conditions. The stress of illness may accentuate the stress of living in a different culture”¹². One Meshketian Turkish patient readily expressed these concerns:

“I don’t know, maybe I’m stressing here. Because, you see, I left all my relatives there [in Krasnodar]. I have seven children. Two daughters are here, one in New York and one in Maryland. Four daughters and one son were left in Russia. So I worry. So maybe that’s another reason I have high blood pressure. All my brothers and sisters were left

Moreover, as described in the introduction, this particular population has experienced a number of horrific and psychologically debilitating events in the course of their history, and all of the patients interviewed for this study lived through one or more of these traumatic events. One patient in particular spontaneously described the Fergana Massacre as well as the discrimination and harassment in Krasnodar. He claimed the following:

“If with every step you are insulted, if you are not considered a human being, it affects your psyche. Every one of our people who came here, every one is a little abnormal, because they are sick of this constant humiliation.” [male patient with hypertension]

Thus, when treating the Meshketian Turks, health care providers should be sensitive and aware of both the general stress faced by immigrants as well as the particular and painful stressors facing this population.

Overall, the subjects of this study expressed satisfaction with the doctors and the care provided at the International Family Medicine Clinic. The patients appeared confident in doctors’ orders and deferent to their knowledge. Few problems with regard to access to care and medications were reported. The most common problem was the lack of medical insurance for some working, middle-aged patients. Interestingly, a number of patients attempted to pass messages or solve problems through the interviewer who could speak both Russian and English fluently and had access to their primary care physician. It is unclear whether this occurred because the patients felt uncomfortable coming to their doctor directly with these problems or that they felt that they were not getting through to the doctor despite the use of interpreter services. Thus it appeared that the biggest incentive for participation in this project was not the \$25 gift certificate, but access to Russian-speaking personnel.

RECOMMENDATIONS

A few concrete recommendations can be made with regards to care for the Meshketian Turkish refugees with chronic medical conditions. Foremost it is very important that health care providers educate their patients about the nature of chronic conditions. A number of written resources in Russian exist that could be used for this purpose. However, note that it is important to read through these sources carefully as

many of them, especially those found on the Internet, are either out of date or incorrect. Several of these resources were collected for this study and passed on to the participating patients. It is also recommended that doctors be aware and on the look-out for psychological illnesses in this population, specifically depression and post-traumatic stress disorder.

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