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Case Report

A refugee's perspective on their neurosurgical care in North America

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Abstract

Background: There is a growing population of refugees within North America and an increasing awareness of their unique medical requirements. These requirements include both a well-recognized need to understand the different pathologies that can present in these patients as well as the rarely described need to understand their unique perspective and how this can impact their medical care, especially for routine neurosurgical conditions. This paper highlights a refugee's perspective toward the medical system in North America and documents how several aspects of this unique perspective hindered or delayed the care for the management of this patient with a cervical cord tumor.

Case Description: A 34-year-old female Somalian refugee presented with an ependymoma to Vancouver General Hospital 3 days after arriving in North America. The tumor was removed through a standard posterior cervical laminectomy approach. The patient and her care workers were interviewed 6 months postoperatively to determine if any aspects of care were negatively impacted by her refugee status. Problems related to communication, medical history, mistrust of care workers, familial support, and access to follow-up care were recognized and recommendations for improvements provided.

Conclusions: It is well known that the North American physicians must be familiar with the unique spectrum of medical conditions within the refugee community. This paper highlights that physicians must also be aware that refugees may have a unique perspective on our health care system that can negatively influence their care for even routine neurosurgical conditions.

Key Words: Neurosurgery, refugee care, spinal cord tumor

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INTRODUCTION

Each year more than 30,000 refugees arrive in Canada,[4] and 70,000 arrive in the United States.[10] Many have been forced to leave their homeland because of war, political and ethnic violence, social discrimination, or natural disasters.[8,12] By virtue of their desperate circumstances, refugees often arrive in North America with a substantial health burden[3,9] and are recognized

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as a vulnerable population.[1,2] Guidelines have been published to help physicians manage the common health adversities faced by refugees: Communicable diseases and psychiatric trauma.[8,9,12] These publications help familiarize physicians with conditions they might not see in their regular practice.[7]

The refugee population can also develop the common medical and surgical conditions that are routinely managed in the North American healthcare system. In this setting, the refugee may have unique personal issues or cultural beliefs that hinder the implementation of what their physicians and surgeons believe to be ideal care. This was the case during the management of a recent refugee to North America with quadriparesis due to a cervical spinal cord ependymoma that required neurosurgical intervention. The patient's unexpected responses to the proposed standard treatment for her condition hindered her care, and will be discussed. The patient was interviewed in her home 6 months after surgery to determine her perspective what areas she would recommend improving. The treating neurosurgeon, nurses, social worker, and translators were also interviewed to determine what aspects of care were affected by the patient's refugee status and what recommendations they would provide.

CASE REPORT

This 34-year-old woman arrived in Canada as a refugee 3 days before presenting to the Emergency Department. She had a 2 years history of progressive right hemiparesis leading to paralysis and a 1-year history of dysphagia for solids and progressive left hemiparesis. On examination, this 150 cm, 30 kg female was malnourished and spoke only Somali. She had contractures of the paralyzed right limbs with pyramidal weakness (Medical Research Council [MRC] Grade 3–4/5) in the left limbs. Magnetic resonance imaging (MRI) demonstrated an enhancing intra-axial upper cervical cord tumor [Figure 1a]. Nutritional supplementation was attempted with a nasogastric tube to improve nutrition prior to surgical intervention, but refused by the patient. The tumor was removed through a posterior cervical laminectomy with electrophysiological monitoring. The pathology was an ependymoma WHO Grade 1 and follow-up imaging showed no residual tumor [Figure 1b]. Her left sided weakness and dysphagia resolved within a few weeks (MRC Grade 5/5 and full oral diet) but her right arm and leg function continued to be hindered by contractions despite regaining anti-gravity strength (MRC 3/5 on last examination).

Unique aspects of the neurosurgical care for this refugee

The care of this patient was hindered by the following factors related to her refugee status: Language barrier, lack of medical history, mistrust of care workers, lack of familial support, malnutrition, and access to follow-up care.

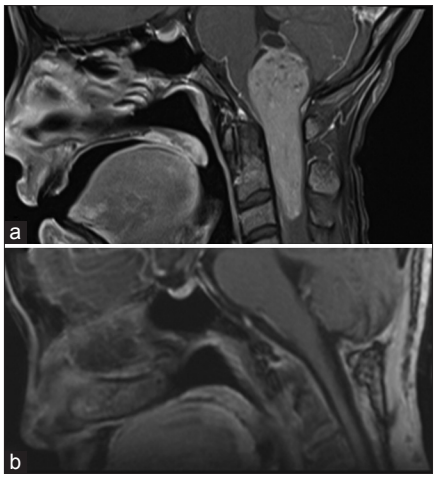

Figure 1:The patient's (a) preoperative and (b) 1-year postoperative sagittal T1-weighted magnetic resonance imaging with gadolinium

Language

The patient spoke Somali, and professional medical interpreters were only available if booked a day in advance. This allowed for formal patient interview and examinations but hindered routine communication with the nurses. The nurses had difficulty explaining what they were doing (e.g., injections), and the patient could not articulate her immediate needs (e.g., pain control or loneliness). Written translation tools were ineffective because the patient was illiterate. This communication barrier hindered treatment (e.g., injection medication refused, explanations for treatment booked the next day) and was particularly stressful for the patient. The immigration support team was later able to provide a full-time, nonmedical, interpreter, but they clashed openly with the medical interpreter creating unnecessary tension for the patient. The constant availability of a translator was clearly better for patient rapport but may have come with less accurate medical translation. We would recommend choosing only one interpreter as having both was counterproductive. This may be circumvented in the future by computer software-based translation, pictographs, or remote interpretation services through phone, or video conference. Although phone interpretation is available at all hospitals, not all physicians are familiar in its use and emergent access is difficult for those speaking less common languages.

Lack of medical history

The history of her presenting illness was provided solely by the patient and her family. The communication barrier produced variation in the history over time and between the patient and her family. There were no collateral records available to verify the medical information. She reported that she had been "diagnosed" with a postpartum stroke

a year prior to her arrival in North America, which was inconsistent with the progressive symptoms that preceded that birth by a year. No information was available on her allergies, medications, previous illnesses or operations, exposure to infectious diseases, or magnitude of weight loss. The patient denied exposure to tuberculosis (TB) but her husband later reported that he was being treated for active TB. This lack of history delayed the initiation of appropriate infectious isolation precautions on the neurosurgery ward. The lack of a complete medical history, therefore, delayed appropriate diagnostic tests for the patient and potentially put the staff at risk for exposure to TB. It would be very helpful in the future if refugees were provided with a standardized form detailing their past medical history by the physicians screening their application.

Trust of care workers

On multiple occasions, the patient agreed to an intervention explained by her physician but later refused to allow the nurse to perform that intervention. We initially incorrectly assumed she understood that a procedure could be explained by one person and performed by another. A repeat explanation with all team members present facilitated some treatments (injected medications) but not all (nasogastric feeding). When interviewed later, the patient could not accept that the immediate discomfort of a nasogastric tube provided a greater but delayed benefit of preoperative nutritional supplementation. The patient later reported that it was stressful for her to meet new nurses each shift. From the patient's perspective, new caregivers were strangers and, therefore, might not be trusted. White *et al.* put forth the idea of a four-staged approach to help facilitate team-based medicine specifically for Somali refugee populations.[11] An emphasis on patient education as well as empathy toward a patient's specific concerns, even if not the most medically pertinent, led to a significant increase in compliance with medical referrals. Parallels can be drawn to this case in that a standard approach focusing on building trust could help ease patient tensions with large medical teams and ultimately facilitate better care. This lack of trust and the associated delay in care could be addressed in the future by introducing a core group of nursing staff accompanied by an interpreter, as well as adding their pictures, to a team photo that could be referenced by the patient. The staff and patient later reported that there was an expectation that this patient adjust to our western culture and medical model faster than was reasonably possible given her background and recent arrival.

Lack of familial support

In this case, the patient's family was housed an hour away, and one child was simultaneously admitted to a pediatric hospital. Travelling by public transport was unfamiliar to the family and described as frightening. As a result, the patient was unintentionally isolated. According to the patient, this was one of the most stressful aspects of her care. In the future, every effort should be made to maintain family support, whether, that is, through onsite housing services or transportation allowances for family members.

Malnutrition

Malnutrition is an uncommon problem in neurosurgical patients. In the last 19,935 consecutive admissions to the neurosurgical service at Vancouver General Hospital, only 3 (0.015%) had a concurrent diagnosis of malnutrition. In this case, the patient had survived for a year drinking only the milk from her cow. Her body mass index (BMI) was 13.1 kg/m^2 which would be the most severe (Grade III) of underweight categories according to the classification reviewed by Ferro-Luzzi *et al.*[6] Extremely low BMI increases the risk of infection, wound dehiscence, and mortality.[5] The treatment of this patient's malnutrition was hindered preoperatively by her dysphagia for solids and refusal of nasogastric supplementation and postoperatively by her refusal to eat hospital food (she would eat only goat meat provided by her family). In hindsight, a more coordinated effort by the entire team to communicate the necessity to provide nasogastric supplementation may have been successful.

Access to follow-up care

Transportation and language barriers continue to present difficult but not insurmountable obstacles for the patient. A follow-up MRI of her spine was delayed several times because the patient did not understand the need for this. All office appointments have been canceled because of her family's difficulty in navigating the public transportation system and potentially due to the cost of travel. Ultimately, patient follow-up has been coordinated by her family physician, and there was a single home visit by the neurosurgical team.

CONCLUSIONS

Refugees entering North America bring both uncommon illnesses and unfamiliar perspectives toward their medical care. Guidelines to familiarize physicians with the unique medical burden faced by refugees have been widely published. There has been little or no literature on how a refugee's perspective might influence their care when treated for routine neurosurgical disorders. This unique barrier can hinder or even block the usual care provided to patients. This case report highlights how difficulties in communication, lack of medical history, mistrust of care workers, lack of familial support, malnutrition, and poor access to follow-up care hindered the neurosurgical treatment of this patient. Recognizing these potential difficulties is the first step toward the addressing them. Additional work needs to be done to understand how our system can best care for refugees, what biases

are faced by refugees seeking medical attention and whether variations in care are acceptable to the refugee population. Ultimately, our patient was very happy with her care but in retrospect, the delivery of her care could have been more efficient and less stressful.

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Conflicts of interest

There are no conflicts of interest.

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