



The  
CENTER for  
VICTIMS of  
TORTURE

# Improving Well-Being for Refugees in Primary Care:

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A Toolkit for Providers

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# Introduction and Guiding Principles

## CHAPTER 1

### CASE EXAMPLE

Paw, a recently arrived refugee, gets a phone call one morning. It's an interpreter telling her she has an appointment. She doesn't remember making the appointment, but the interpreter explains that it's with a doctor, and that makes her remember the outstretched hand of her resettlement worker, giving her a card with a time and date written in English. The interpreter tells her a taxi will come for her, but when an English-speaking driver arrives at her door and says her name, she hesitates. Can she really trust this person to take her to the right place? In the end, she gets in, because she's hopeful the doctor will help her stop the headaches, nightmares and pain. Yes, she sometimes forgets things, but what she can't forget are all of the horrible things she lived through. The driver stops in front of an office building and says something, so she gets out of the car. Inside, someone behind a computer is smiling at her and motioning at her to come forward, and when it becomes clear that she doesn't speak English, the receptionist calls over an interpreter. She helps Paw check in for her appointment, and explains that her name will be called soon. Paw sits by herself in the waiting room and looks around worriedly. She sees posters on the wall in languages she doesn't recognize. She's nervous. She doesn't know what she's supposed to say or do, and her mind is filled with questions:

- What kinds of things can I talk to my doctor about?
- Is my doctor going to ask me a lot of questions?
- What if I don't know how to answer the questions?
- Will the doctor be nice?
- Will my health problems be solved today?
- I wonder if my doctor is going to ask about my past. Should I talk about my past?
- Will I ever be a healthy person again? What if I never get well?
- What if I don't remember what the doctor tells me; what will I do?
- How will the doctor understand me? What if I don't like the interpreter? Will I have the same interpreter who just helped me?

We, as health care providers in the United States, would benefit by asking our own questions about this meeting as well. Will we:

- Assess Paw in a way that comprehensively addresses her health concerns?
- Understand how Paw's experiences, health literacy and education level impact her understanding of her problems and treatment?

- Be able to offer a clear treatment plan that Paw will understand how to implement?
- Recognize if Paw's basic needs are being met and prioritize identifying ways to help her meet those needs?
- Recognize and attend to her mental health symptoms?
- Work well with an interpreter to accurately understand Paw's problems and respect her privacy and autonomy?
- Discuss any medication recommendations with details that will help Paw take the medicine safely, accurately and effectively?
- Help her address barriers to her ongoing care so that she can experience health improvements?
- Be able to work with refugees like Paw in a professionally sustainable way? Or will we get burnt out from doing this work?

## Introduction

This toolkit will address these questions and more. Paw's story will be used throughout to highlight problems, solutions, challenges and strengths when **refugee** patients and U.S. health care providers collaborate and bridge cultural divides to offer quality health care.

In order to be effective as health care providers, we need to be clear about the reality for refugee patients with whom we work. Many have experienced the devastation of their homes and villages. Many have survived torture and various war-related traumas. Many have witnessed the torture and killing of family members. Some were used as human shields and used to clear landmines. Their ways of life and livelihoods were taken from them, and chaos and deprivation became normal. Out of desperation and hopelessness, after years or decades of living in transitional settings including impoverished and sometimes dangerous refugee camps, many have relocated to safe harbors in countries they never imagined inhabiting. With a lifetime's worth of knowledge suited to their former environments, refugees must acculturate to Western norms and customs almost immediately upon arrival in the United States.

Health care providers may mistakenly believe that resettled refugees are now free from traumatic experiences. This is often not the case. Refugees who are affected by illness or injury, or who feel hopeless, helpless and overwhelmed, often struggle with the challenges of work and school. **Acculturation**, racism and discrimination, poor educational opportunities and poverty create additional adversity and even trauma for this vulnerable group. As health care providers, we have an opportunity to positively influence refugees' life trajectories if we understand and attempt to mitigate the harm of these circumstances. We can serve as powerful witnesses to past abuses of power and offer opportunities to transform devastation, suffering, cruelty and abuse into safety, healthy relationships, understanding and healing.

### DEFINITIONS

#### **Refugee:**

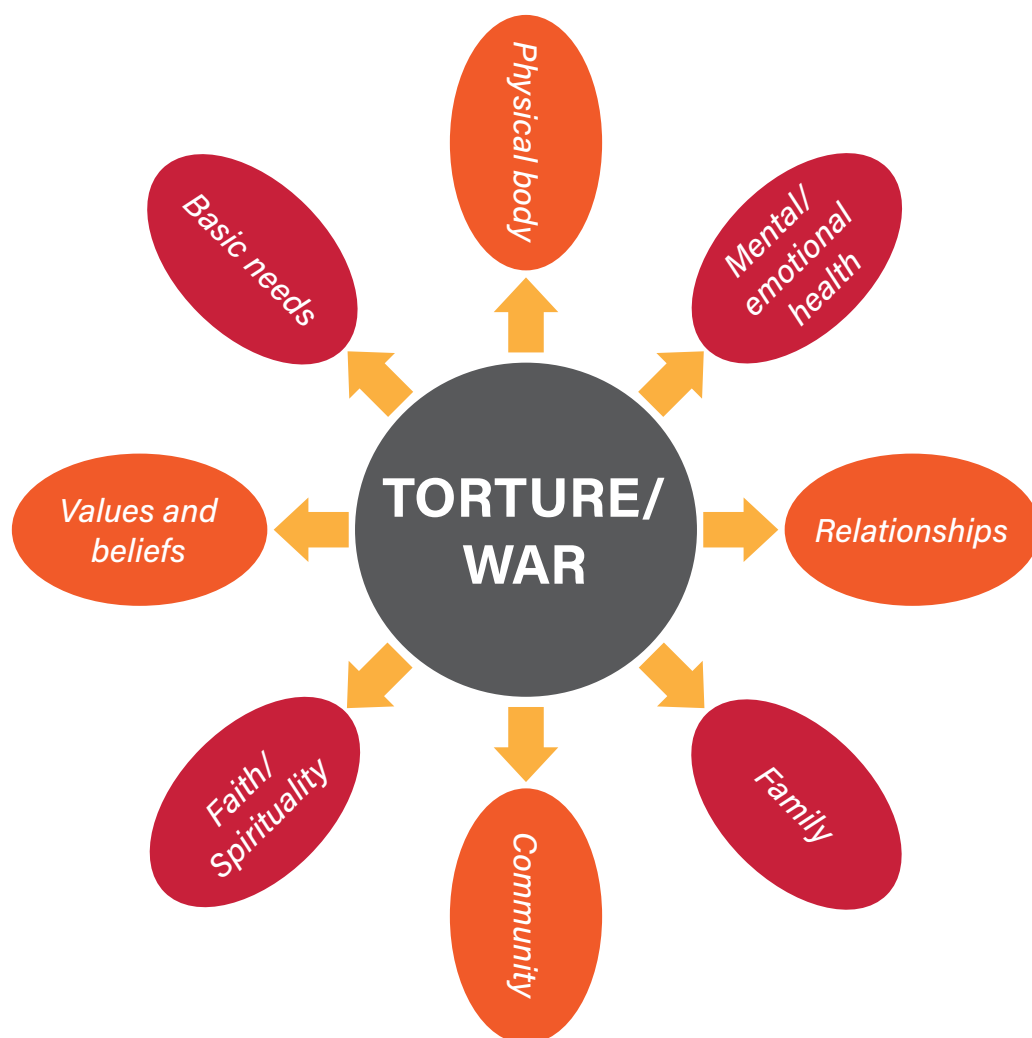
*Someone who has been forced to flee his or her country because of persecution, war or violence. A refugee has a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group. (United Nations Refugee Agency, n.d.)*

#### **Acculturation:**

*The process of adapting to the traits and customs of another culture.*



***Torture and war impact many aspects of a survivor's life.***



## **Background: Health Care for Refugees in the United States**

Since the end of World War II, the United States has served a prominent role in offering sanctuary for refugees. U.S. health care providers increasingly understand the medical needs of people from different parts of the globe. Physical health screening tools developed and adapted over the years have ensured that newly arrived refugee patients receive the immunizations and immediate treatments they need for their physical health conditions. More recently, refugees' psychological health needs have received greater attention, and mental health screening tools have been developed to address these needs as well. However, detecting and treating mental health conditions is no simple task, especially given the intersection of physical and mental health problems among refugees, and the challenge of cross-cultural communication.

To meet these challenges, clinicians must hone their skills in culturally competent health care. Structures, for example culturally validated screening tools are crucial to ensure that refugees have access to effective care. Access has improved in some areas of the country through federally required changes such as requiring facilities to use interpreter for appointments covered through public health insurance. Nonetheless, there are still many unaddressed barriers that result in poorer health care outcomes for refugee populations.



The health care system in the United States is designed to treat health needs when patients bring their concerns to the attention of a health care provider. Primary health care providers address these concerns and refer to specialty care when appropriate. Refugees who are unable or unwilling to explain their problems in a way that health care providers can understand often suffer in silence with unaddressed needs. As the culture in U.S. health care continues to shift, clinics, as public health institutions, have opportunities to better meet the needs of individuals and communities suffering from both physical and mental health problems. Refugees, who are among the most vulnerable populations in the United States, can thrive when providers attune to cultural dimensions of their health. These dimensions include community needs; cultural expressions of pain and distress; and acknowledgment of the influence that experiences of trauma, poverty and limited educational opportunities have on refugee health.

## Tailoring Health Services for Refugees

Paolo Freire, philosopher and educator, said, “There is no teaching without learning” (2000). For health care providers, this means that serving refugee communities’ health care needs requires fostering an intimate connection between Western biomedical knowledge and the understanding of refugee patients’ environments, both past and present. Unfortunately, much Western training in medical and mental health neglects the need for cultural specificity and assumes that goals and concepts can be applied universally. This promotes rigid notions of what health and “normal” behavior look like. As health care providers, we need to combat this rigidity often present in our training and interventions, and look for ways to work in partnership with refugees who embody cultural experiences that are often different from our own.

Some experiences are all too common in refugee populations, such as the high prevalence of the experience of torture (up to 44%) amongst refugees resettled in the United States (Higson-Smith & Vukovich, 2015). That being said, no two refugee experiences are the same. It is critical for providers to avoid stereotyping refugees, as with any group, and clinics may benefit from integrating concepts such as Christensen’s **health reference point** that help emphasize health care from refugees’ perspective.

Relationships are at the core of understanding patients. Providers may regularly miss the mark in trying to offer treatment to refugee patients if they are neglecting important aspects of relationship building. War trauma and torture are intentionally used to disrupt an individual’s ability to be in relationships with others. Successful treatments must incorporate sensitivity to trauma healing throughout patient-centered practices. In this toolkit, we provide strategies to provide quality health care while building strong relationships with patients that promote their involvement and empowerment in the process of healing. We know that patients engage more in their treatment when they feel heard and understood by health care providers. To foster this connection, health care providers must focus on building relationships, promoting safety and stabilization, understanding the community’s experience of trauma and accounting for the power dynamics of patient-provider relationships.

### Understanding Cultural Competence

*Cultural competence is aspirational and process oriented. It is not a static state of being. Sue and Sue (2013) offer a multidimensional model for conceptualizing cultural competence for counseling professionals. Their three ways to actively work toward developing this competence also apply to other health care professionals offering cross-cultural care. The culturally competent health care provider develops the following:*

1. **Awareness** of their own assumptions, values and biases.
2. **Understanding** of worldviews culturally diverse patients hold.
3. **Skill** in using appropriate intervention strategies and techniques.

### DEFINITION

#### **Health reference point:**

*The level of mental, emotional and physical health people believe possible or necessary to make the progress they seek, at a particular life juncture, given their circumstances and the trade-offs they are willing to make (Fogg, 2017).*



## *Safety and Stabilization*

For refugee patients, the importance of safety and stabilization cannot be overstated. Patients presenting in crisis need to have the basic needs of safety, food and shelter addressed before most other aspects of their health care can be prioritized. Patients' energy will be directed towards self-protection until safety is felt (Levy, 2017). CVT draws on the trauma treatment lens that Judith Herman (1992) offered in her work *Trauma and Recovery*. Safety and stability, along with a healing relationship between the patient and provider, are essential for trauma treatment. Patients with long histories of instability or trauma often need significant treatment focused on safety and stability before treatment focused on additional stages of recovery that include integrating traumatic experiences into one's life and building a post-trauma life.

Many resettled refugees are at the beginning of their trauma recovery process, even when they have been in the United States for a long period, as untreated trauma can linger for decades after its initial onset (Marshall et al., 2005). Each interaction a trauma survivor has with another person is a potential opportunity for a healing or traumatizing experience. This toolkit emphasizes the central role that health care providers can contribute in establishing experiences of safety and stability (Chapter 5). Health care providers who consider holistic care and are attuned to the basic needs of a patient (e.g., housing stability or access to adequate nutrition) play a vital role in complementing the stability they offer through medical treatments.

## *Power Dynamics*

Power dynamics impact relationships in the health care setting. Refugee patients access care in different ways depending on historical experiences of colonization, experiences of trauma and torture, and cultural expectations regarding power and social roles. Many refugees come from contexts in which persons with fewer financial resources, social or political connections, or years of education have fewer human rights and far less power in navigating services in their community. Health care providers need to be aware of how power is perceived and acted upon in these relationships. When these power dynamics are understood and addressed, providers and patients are able to successfully implement health care treatment plans that offer health and healing. Whereas torture and trauma experiences often actively disempower and silence patients' voices, health care experiences can play a significant role in empowering and bringing voice to refugee patients' needs and experiences.



## Toolkit Purpose and Overview

This toolkit is intended for people who work in health care with refugees, including doctors, nurses, psychotherapists, social workers, community health care workers, interpreters, care guides, and other associated professionals.

Throughout this toolkit we will review ways for providers to:

- Develop greater understanding of refugee patients' realities and health perspectives through relationship-based techniques and culturally humble, curious approaches.
- Advocate for holistic, trauma-informed and patient-centered health care systems that take responsibility for addressing barriers refugees face when accessing and receiving care.
- Support empowerment, confidence building and a sense of belonging among refugee patients.

While this call to integrate new ways of improving health care outcomes for refugees sounds appealing, it can feel burdensome to already stretched health care providers. But improving care for refugees entails redirecting energy, not "doing more." The goals discussed in this toolkit can be accomplished while maintaining time boundaries. For

example, determining a holistic plan of care for a refugee may take more effort up front but will pay off with fewer visits, fewer costly assessments, greater adherence to medications prescribed and greater satisfaction in addressing overwhelming challenges that the refugee patient faces. We providers hold privileged positions that allow us to witness the impact of war and torture on a refugee community, acknowledge the significant harm these experiences cause, contribute to experiences of safety in establishing lives in a new country, and help rebuild meaningful lives.

The impact of war and persecution is profound and complex. War and torture intentionally disrupt individuals and communities in biological, social, psychological and spiritual domains. Integrated behavioral health care and multidisciplinary approaches are generally recommended for refugees, due to the multifaceted ways that torture and war trauma impact health.

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### *The Healing Hearts, Creating Hope Research Project*

This toolkit is a product of clinical learnings from a five-year research project by clinicians from the Center for Victims of Torture (CVT) called Healing Hearts, Creating Hope (HH). The HH study was conducted from 2013 to 2017 to examine the effectiveness of co-locating specialized psychotherapy and mental health case management services for refugees in primary care settings. As far as the researchers know, the study is the first randomized control trial in the United States to investigate the impact of delivering specialized behavioral health care for refugees within primary care on post-trauma symptoms and social functioning in the United States. CVT clinicians and researchers collaborated with two primary care clinics in St. Paul that serve large caseloads of refugee patients to conduct the study: the Health East Roselawn Clinic and the University of Minnesota Physicians Bethesda Clinic.

Previous research conducted by CVT and its community partners found that refugees face significant barriers when accessing mental health care. Primary care clinics have limited capacity to attend to the long-term psychological and social needs of their most depressed refugee patients, even when behavioral health care is available at the clinic. Patients needing a referral to an external mental health provider often failed to successfully engage with services at a new location. Logistical barriers (e.g., lack of transportation, inability to reach the patient by phone, language and memory trouble) also impede patients' abilities to follow up on external mental health referrals. Additionally, the concept of mental health can be unfamiliar to refugees, and refugee patients may not understand how a mental health provider could support their health and resettlement.





With these experiences in mind, CVT partnered with the clinics to bring specialized psychotherapy and mental health care management services in-house. CVT designed a research study and obtained grant funding to respond to the following questions:

- 1) Are the CVT treatment services more effective in reducing common post-trauma symptoms and social functioning as compared to treatment as usual at the primary care clinics?
- 2) Do the CVT treatment services (specialized psychotherapy and mental health case management) result in cost savings as compared to treatment as usual at the primary care clinics?

Resettled Karen refugees from Burma and Thailand (aka Myanmar)<sup>1</sup> were chosen as the target population for this study because of the high population served in the primary care clinics and the high rate of torture and war trauma present in the community.

When implementing this program, HH clinicians used the frameworks and principles described in this toolkit. Information is included from this research that directly supports clinical observations, in boxes called Data for Thought. More generally, clinical learning from this research project is infused throughout the toolkit.

## Format of Chapters

This toolkit is arranged into ten chapters that equip readers to provide quality, holistic health care for refugees. The information in this guide is intended to supplement and enhance medical and mental health decision-making processes. In each chapter, we offer real-life examples adapted from researchers' direct experiences. Each chapter has the same format:

- 1) A case example where providers are not utilizing recommended practices.
- 2) An introduction to the chapter.
- 3) A series of issues to consider on the chapter topic, followed by recommendations.
- 4) A brief summary of recommendations from the chapter.
- 5) A return to the case example where the provider has now incorporated recommendations from the chapter.
- 6) Discussion questions.
- 7) References.

### Chapter 2: The Refugee Experience

This chapter reviews common refugee experiences that providers need to be aware of when obtaining patient histories and providing trauma-informed care.

### Chapter 3: Symptoms, Presentation and Assessment

This chapter reviews complex symptom presentations in refugee patients, highlighting how refugee patients may present symptoms differently than other patients and have different needs that health care providers can address.

### Chapter 4: Treatment Planning

This chapter is aimed at helping health care providers understand the refugee experience to bolster treatment planning in this section.

1. The ruling military regime changed the name from Burma to Myanmar in 1989. Many ethnic minorities in the country do not use the new name as it represents a repressive regime, and we use the name Burma to reflect this fact.



**Chapter 5: Attending to Basic Needs**

This chapter reviews ways to promote stabilization and attend to basic needs within your role as a provider.

**Chapter 6: Behavioral Health Interventions**

Common behavioral health interventions used routinely by providers working with refugees are described in this chapter.

**Chapter 7: Working with Interpreters**

How to work skillfully with interpreters is detailed in this chapter, with emphasis on building strong relationships with interpreters in order to improve communication. This chapter also highlights the challenges of working in small communities and respecting the privacy of patients.

**Chapter 8: Medication Use**

This chapter focuses on medication challenges and strategies for improved medication adherence for refugees. The chapter is not only for prescribers, as careful attention to medication concerns is often required in order to attain the stabilization necessary for behavioral interventions to succeed.

**Chapter 9: Social Support/Community Level Interventions**

This chapter looks at how family, friends and the greater community impact a survivor's health, and offers recommendations for provider interventions.

**Chapter 10: Mitigating Secondary Trauma**

This chapter acknowledges the impact of provider work stress and secondary trauma along with strategies to promote self-care and secondary resilience.

## Thank You

*We have a significant role to play in helping refugee patients, as individuals and as a community, recover from experiences that have been harmful. Health care providers can help refugees by attending to needs that are apparent as well as needs that are hidden, like many mental health needs. If providers treat refugees just like everyone else and fail to consider their unique trauma histories and lack of experience with Western health care norms, we risk retraumatizing refugee patients, making their conditions worse and discouraging them from seeking care in the future. Refugee patients often struggle to survive before they can thrive. But they can thrive and heal from wounds. Refugees have always been a core part of the American experiment; they continue to enrich the United States with new customs, viewpoints, food, arts, technologies and ideas. The authors are honored and humbled to be a part of their journey; thank you for joining us.*



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# The Refugee Experience

## CHAPTER 2

### CASE EXAMPLE

Remember, Paw? We left her waiting in reception area of a primary care clinic. Paw, as you'll remember, is a recently arrived refugee. While Paw is waiting, an interpreter comes over and helps her fill out some paperwork. Here's some basic information about Paw, some of which ends up on the paperwork and some of which doesn't:

- 40 years old.
- Cisgender female.
- Heterosexual.
- Married (second husband) with children.
- Fluent in Sgaw Karen.
- Lives in St. Paul, Minnesota with husband, children and mother-in-law.
- Works part-time as a home health aide for her mother-in-law and also stays home to care for her children.

Today, the clinic is running a pilot project. If the doctor who meets with Paw thinks she might have experienced torture or war trauma, Paw will be referred for further mental health screening to identify past war and torture experiences and current mental health symptoms. The role of the screener (who is a licensed mental health professional) is to identify war trauma survivors with mental health symptoms and then complete a brief assessment to determine if an internal referral to behavioral health services is indicated. When the doctor meets with Paw, it's clear that she may have experienced trauma and Paw is immediately referred to this mental health screener. After working through the questions on the assessment tool, the screener asks some follow-up questions:

**MH Screener:** *You said you experienced war and other difficulties back in Burma. I'd like to understand some of your experiences.*

**Paw:** *Life there was good in Burma.*

**MH Screener:** *Before you fled?*

**Paw:** *Until we were forced to flee.*

**MH Screener:** *Who did you live with?*

**Paw:** *I lived with my husband.*

**MH Screener:** *I'm sorry. I don't mean to upset you. I'd like to know more to help you heal, but it's important that you feel safe.*

- Paw:** *Many bad things happened.*
- MH Screener:** *I'll try to make sure you don't feel overwhelmed.*
- Paw:** *My first husband was killed when a bomb blew up on our path. I was pregnant at the time when we ran and lost my baby too. I wanted to die. I did not get to bury her.*
- MH Screener:** *You suffered incredible losses.*
- Paw:** *Yes.*
- MH Screener:** *You made it to a refugee camp and stayed there prior to coming to the United States?*
- Paw:** *I made it to Mae Sot and stayed there with help of family. My oldest child was sick there and no help and no medicine. He died; I don't know why. I could not move for a month.*
- MH Screener:** *You wanted to die as well?*
- Paw:** *Yes.*
- MH Screener:** *How long did you live at the camp called Mae Sot?*
- Paw:** *I don't know. Many years.*
- MH Screener:** *Have you spoken about these experiences with your doctor?*
- Paw:** *No. I don't talk about these things. They create heavy heart and headache. I don't want to talk about it. My family tells me not to talk about it because I get upset. I am still very scared for my family in Burma.*
- MH Screener:** *I know it's difficult, but we can talk about these experiences in a way that helps you to heal.*
- Paw:** *Remembering makes me feel heaviness in my neck and head.*
- MH Screener:** *I'd like to recommend that you meet with the therapist in our team here at the clinic. This person will talk with you and listen and try to better understand what you lived through. She'll help you with feelings like sadness or worry or heaviness you are having now. Would you be interested in that?*
- Paw:** *I think so. I would like to think about it.*

In the end, Paw meets clinical cut-offs for symptomatic depression, anxiety and PTSD according to reported levels of distress from the refugee screening assessment.



## Introduction

*For those growing up in a safe environment, it can be difficult to relate to the long, slow suffering of deprivation and uncertainty that many refugees have experienced in their lives. This chapter is divided into two sections:*

- 1) *background information on the refugee experience and*
- 2) *recommendations to help health care providers better understand refugee patients' past experiences to set the ground work for assessment and treatment planning.*



## PART 1: BACKGROUND INFORMATION

Refugees, by definition, are people resettled in the United States due to a well-founded fear of persecution and an inability to return to their country of origin. They have often directly experienced war, torture or other human rights abuses. These experiences have a profound impact on physical and mental health symptoms. Leaving one's country and adapting to life in a new environment can pose additional serious threats to physical and mental health as well.

### Who is a Refugee?

It is important to understand the legal status of people coming from different circumstances. The following chart distinguishes between refugees, asylum seekers, and migrants or immigrants:

Legal Status	UNHCR Definition
Refugee	<ul style="list-style-type: none"> <li>Someone residing outside their country of origin because of feared persecution, conflict, violence, or other circumstances that have seriously disturbed public order, and who as a result require international protection.</li> <li>This status is defined and protected in international law, and granted prior to U.S. resettlement.</li> </ul>
Asylum Seeker	<ul style="list-style-type: none"> <li>Someone who files a request for sanctuary from feared persecution after arrival in a host country (for example, the United States). If approved, the asylum seeker will be recognized as a refugee.</li> </ul>
Migrant/Immigrant	<ul style="list-style-type: none"> <li>Someone choosing to reside outside their country of origin to improve their life by finding work, pursuing education, reuniting with their family, fleeing violence and/or a variety of other reasons. Those fleeing violence may or may not pursue or be able to request asylum.</li> </ul>

Note. Definitions come from the United Nations Refugee Agency (UNHCR), *What is a Refugee?*, retrieved from <https://www.unrefugees.org/refugee-facts/what-is-a-refugee>



## Triple-Trauma Paradigm

Refugees are unable to return home due to well-founded fear of violence or persecution. Refugees often have long journeys of resettlement due to these experiences of violence or persecution. The triple-trauma paradigm (Baker, 1992) is a recognition that trauma is not a singular event that a refugee experienced in the past. Instead, traumatic experiences can occur for refugees and asylum seekers during multiple points of their journey in exile. The triple-trauma paradigm can also apply to migrants or immigrants depending on their circumstances. The table below offers multiple examples of sources of trauma during pre-flight, flight and post-flight experiences.

Health care providers must keep in mind refugee experiences prior to the pre-flight environment. These experiences vary widely. Some refugees experienced long periods of peace and stability with adequate access to medical care and education; their lives, and expectations for their lives, were well established before war or persecution was even a threat. Other refugees experienced conflict and instability without access to adequate medical care or education from an early age. Furthermore, the impact of social class may have affected access to education, employment opportunities and medical care. The sum of these experiences impacts refugees' health care expectations and their sense of their life's trajectory.

### PRE-FLIGHT

(Note: Symptoms often develop as adaptations that promote survival under life-threatening circumstances.)

- Harassment, intimidation, threats.
- Fear of unexpected arrest.
- Loss of job/livelihood.
- Loss of home and possessions.
- Disruption of studies, life dreams.
- Repeated relocation.
- Living in hiding/underground.
- Societal chaos/breakdown.
- Prohibition of traditional practices.
- Lack of medical care.
- Separation, isolation of family.
- Malnutrition.
- Need for secrecy, silence, distrust.
- Brief arrests.
- Being followed or monitored.
- Imprisonment.
- Torture.
- Other forms of violence.
- Witnessing violence.
- Disappearances/ deaths.

### FLIGHT

- Fear of being caught or returned.
- Living in hiding/underground
- Detention at checkpoints / borders.
- Loss of home/possessions.
- Loss of job/schooling.
- Illness.
- Robbery
- Exploitation: bribes, falsification.
- Physical assault, rape, or injury.
- Witnessing violence.
- Lack of medical care.
- Separation, isolation of family.
- Malnutrition.
- Crowded, unsanitary conditions.
- Long waits in refugee camps.
- Great uncertainty about future.

### POST-FLIGHT

(Note: Symptoms often develop as adaptations that promote survival under life-threatening circumstances.)

- Low social and economic status.
- Lack of legal status.
- Language barriers.
- Transportation, service barriers.
- Loss of identity, roles.
- Bad news from home.
- Unmet expectations.
- Unemployment/ underemployment.
- Racial/ ethnic discrimination.
- Inadequate, dangerous housing.
- Repeated relocation/ migration.
- Social and cultural isolation.
- Family separation/ reunification.
- Unresolved losses/ disappearances.
- Conflict: internal, marital, generational, community.
- Unrealistic expectations from home.
- Shock of new climate, geography.



**Pre-flight** is defined as the period of time when persecution or societal collapse may have started but physical relocation has not yet been pursued. Many traumatic experiences happen during this time, including murder, disappearance and torture. Societal upheaval at this time contributes to confusion about the best course of action to take. The need to either live in hiding or otherwise significantly change one's daily routine underscores the experiences of intense fear. Refugees wrestle with managing these overwhelming experiences while weighing the risks and benefits of staying and struggling or fleeing in hope of safety.

**Flight** is defined as an individual's migration period, starting when they leave their home and ending when they have attained durable or permanent resettlement. An individual's experience in a refugee camp is considered part of this flight period. Experiences across these periods vary widely for refugees. Some refugees temporarily resettle in cities or uncontrolled settings while others live in a designated refugee camp. For example, in Nairobi and other urban refugee settings, the United Nations Refugee High Commissioner for Refugees (UNHCR) initiated a pilot operation to integrate refugees within the Kenyan population (P. Traspas, personal communication, September 6, 2017). In these urban settings, refugees have freedom of movement with only very basic services from UNHCR and partners. Refugees struggle on a daily basis to have basic needs met (e.g., food, shelter, education) and often are unable to work legally. Protecting refugees in this setting is very challenging.

While refugee camp experiences vary, there are some commonalities. Refugee camp environments are often controlled spaces where food rations are offered. If refugees attempt to seek work outside of these spaces to aid their families, worries about being caught and possibly tormented by police are a real concern. Refugee camps are also often unsafe. Fires, extreme heat or cold, unsanitary conditions, crimes such as robbery and sexual assault, and additional violence occur. The immigration process starts for a refugee during this stage of flight. Legal documents including birth certificates and passports may be lost during flight. Small tasks such as obtaining an ID picture can present time-consuming or even insurmountable obstacles. Many refugees spend years if not decades in these deprived circumstances, and some refugee camps become places where generations live out their entire lives (e.g., Palestinian camps in the Middle East).

Separation from family members often occurs for a number of reasons and can also drag on for decades. Once resettled in the United States, refugees can apply for family members to come for reunification through visas that can take as long as 10 to 15 years to procure. The experience of **ambiguous loss** may occur at this time. Status for resettlement may change regularly, and there may be rumors of repatriation. Separation and divorce bring additional legal challenges. Refugees in impoverished and stressful circumstances are at increased risk for domestic violence due to higher levels of stress.

## Data for Thought

According to the Healing Hearts study (Esala, Hudak, Eaton, and Vukovich, 2018), in 2017, 90% of CVT clients at the St. Paul Healing Center reported loss of socioeconomic status as a result of torture or war trauma events. Additionally, over 85% of clients experienced physical violence, harassment and loss of occupation. Moreover, witnessing violence or harassment against family members and being forced to live in hiding are common experiences reported among refugee and asylum seeking clients prior to resettlement. Ethnicity, political affiliation and gender (for women) are the top three reasons that clients report experiencing torture and war trauma.

## DEFINITION

### **Ambiguous loss:**

*A loss that remains unclear, with "uncertainty or a lack of information about the whereabouts or status of a loved one as absent or present, as dead or alive, [that] is traumatizing for most individuals, couples, and families." (Boss, 2007).*



**Post-flight** is defined as the period of time after a durable resettlement opportunity has been realized. For some, this means returning to a homeland that is now safer or at peace. For others, this means integration into the host community where they initially fled and found refuge. For yet others, this means resettlement in a host country other than the one to which they initially fled. Refugees frequently experience a feeling of relief immediately after they arrive in the United States, though many may have long-term dreams of returning to their home country. In the United States, refugees may be reunited with family or friends following long periods of separation. Parents may have the chance to send their children to school for the first time. Economic opportunities such as authorized employment may now be available. Refugees may feel a sense of accomplishment and permanent stability following many years of fleeing and temporary resettlement.

Sources of distress, however, soon emerge. Refugees begin life in the United States with a debt to pay for their airline tickets. While short-term assistance is offered for food and housing (generally for three months), meeting these needs independently in a matter of months without knowing the national language and with minimal resources is extremely difficult. Refugees face intense pressure to find work and acculturate, and against great odds, many are able to do so. For example, refugee men are employed at higher rates than their U.S.-born peers (Capps & Fix, 2015). A forthcoming study also found that refugees ages 18 to 45 who arrive in the United States with a work permit end up paying tens of thousands of dollars more in U.S. taxes than they receive in benefits over time (Evans & Fitzgerald, 2017; Miliband, 2017). A recent Department of Health and Human Services report found that refugees contributed tens of billions of dollars more revenue to the government than they cost over the past decade (Davis, 2017).

Despite this general success, some refugees are unable to work due to physical health problems, mental health symptoms, family responsibilities, and language barriers. Patients sometimes report feeling that their identity has been taken away and that they are unable to provide for their families in their new country. They feel their skills are no longer valuable. Older adults may feel hopeless about their inability to learn English and the loss of their status

as a culturally valued elder. Miller (2017) and many others have described struggles faced by refugees, and he offers a summary of these challenges as follows:

- Poverty.
- Overcrowded and unsafe housing.
- Unemployment or underemployment, often due to employment restrictions placed on refugees by their host society.
- Social isolation, as family members and friends are left behind or resettled elsewhere.
- Heightened family violence, as marital and family tensions rise due to chronic adversity and parents struggle with continuously high levels of stress.
- Social marginalization of stigmatized groups such as sexual assault survivors, people disabled by landmines or other war-related violence, and children orphaned by violence and displacement.
- The loss of life projects and valued social roles.
- Frequent moves, leading to a sense of perpetual homelessness, a feeling that “this place we call home could be gone tomorrow.”
- Discrimination by the host society.
- The detention of asylum seekers and uncertainty regarding their asylum applications.

Further details regarding common needs faced by refugees during resettlement along with recommendations are detailed in Chapter 5.





While the triple-trauma paradigm emphasizes the negative impacts of each of these three stages, remember that refugees have endured these traumas, showing vast **resilience** and tremendous internal strengths. They have survived against all odds; many of their cohort is dead. The fact that they are even able to attend a medical appointment is a testament to this resilience. Providers who strive to understand how a refugee patient made it through these experiences will better understand patient strengths, resources and skills that can be used to focus energy on improved health. While it is easy for providers to feel overwhelmed by the traumas refugee patients have encountered and think of the patient from a deficit perspective, a strengths-based approach that acknowledges a refugee patient's multitude of strengths is a vital counterpart for treatment success. Ongoing assessment and acknowledgement of patient resiliency are critical to understand each patient holistically and build on strengths when treatment planning.

## Common Myths about Refugees

### 1) The United States is the world leader in accepting refugees.

- As of October 2016, 56% of refugees worldwide were hosted by 10 countries in the Middle East, Africa, and South Asia (Le Miere, 2016). These countries account for only 2.5% of global income ("Ten Countries," 2016).

## DEFINITIONS

### Resilience:

*"The capacity of a dynamic system to adapt successfully to disturbances that threaten the viability, the function, or the development of that system" (Masten, 2014).*

### Collective resilience:

*A community's coping processes in which pre-existing social bonds and networks help hold communities together, provide support and protection, and facilitate adaption in times of extreme stress and during the process of resettlement. (Fielding & Anderson, 2008)*



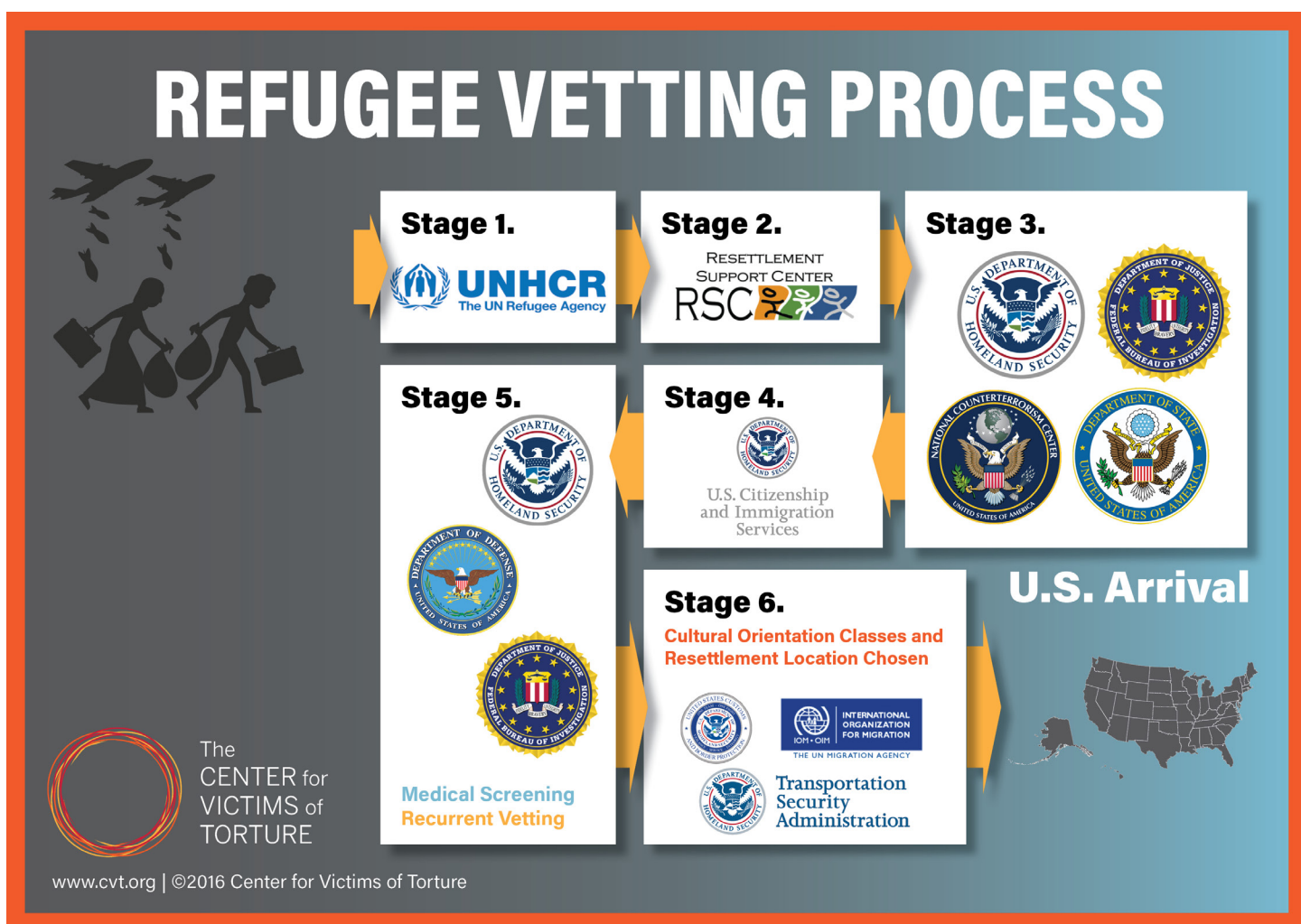
Graphic: Amnesty International from <https://www.amnesty.org/en/what-we-do/refugees-asylum-seekers-and-migrants/global-refugee-crisis-statistics-and-facts/>



- Of the 22.5 million refugees worldwide, only 189,300 people were permanently resettled (2016 figures (United Nations High Commissioner for Refugees). The United States proposed to accept 30,000 refugees in Fiscal year 2019. (U.S. Department of State, 2018).

## 2) It is easy to receive refugee status.

- Of the 65.6 million forcibly displaced people worldwide, only 34.3% (22.5 million) have received refugee status (United Nations High Commissioner for Refugees).
- Refugees are the most thoroughly screened people entering the United States. Below is an overview of the numerous checks, often spanning multiple years, to ensure each refugee meets all security requirements.



Graphic: Reproduced from "Vigorous Refugee Vetting Process for the U.S.," Center for Victims of Torture, retrieved from <http://www.cvt.org/Refugee-Vetting-Process>

### 3) Most refugees live in a refugee camp and receive support.

- The majority of refugees live in urban areas in private residences, not in camps (United Nations High Commissioner for Refugees, 2016).

### 4) All refugees want to come to the United States.

- UNHCR Head of Communications and Chief Spokesperson Melissa Fleming reported all refugees she met with primarily desired to return home (United Nations High Commissioner for Refugees, 2017).
- This hope to return to a country of origin is often only tempered by access to economic, social and civic rights (Kibreab, 2003).
- Refugees may choose to voluntarily repatriate to their country of origin; in 2016 there were more than 552,300 refugee returns which is less than 5% of the refugee population (United Nations High Commissioner for Refugees, 2016).

Other resources available to help understand characteristic refugee experiences include the following:

- "Walking Together: A Mental Health Therapist's Guide to Working with Refugees" (Lutheran Community Services, 2015) found here: <https://form.jotform.us/51666347065157>
- "Psychology of Immigration 101" (American Psychological Association) found here: <http://www.apa.org/topics/immigration/immigration-psychology.aspx>



## PART 2: RECOMMENDATIONS

How should health care providers use this general background knowledge of the refugee experience and apply it to individual refugee patients? The following section offers some practical advice to help incorporate the realities refugee patients have faced to help providers obtain the most accurate information for assessment and formation of the treatment plan.

### *Patient Safety*

Refugee patients, especially those in their first several years of being in a new country, are in the midst of an enormous life transition. Experiencing safety and stability within this change can be difficult but is essential to their recovery from traumatic and overwhelming experiences. Health care providers have an opportunity to help a refugee acculturate and experience improved health and wellbeing. Each individual's sense of safety is different and establishing safety and stability is a process.







## RECOMMENDATIONS

Ask patients about their sense of safety. A patient might not be forthcoming at your first meeting, so continue to assess over time. You will likely need to go beyond a single standard general assessment question such as “do you feel safe?” in order to solicit a full picture. Instead, inquire about specific elements of safety. Examples of specific questions are as follows:

- *Are there certain things that scare you in the United States?*
- *Does it feel safe to ride as a passenger in a car or on a bus?*
- *Do you hear about threats of violence in your country of origin?*
- *Does your apartment feel safe?*

By asking about these areas of a patient's life, you demonstrate that they care for the patient and can credibly help them to understand the variety of new and daunting tasks they encounter. Though it is not providers' role to directly help or fix things for refugee patients in all areas of safety and stability, you have cultural capital and knowledge that your patients can rely on and learn from. Helping them to know how to stay safe in a car, access resources for building language skills, understand available emergency services, and ensure safety in their apartments can go a long way towards improving patients' engagement with their health care providers. Increasing safety and stability will make it more likely for patients to be able to own their health treatment plan and actively work with you to improve their health.

### *Orient Refugee Patients to the Long-Term Impact of Trauma*

For many refugees, trauma, torture and stressful experiences have been all too common. When traumatic loss becomes “normal,” it can be hard to distinguish this suffering from everyday life. Many refugee patients suffer in silence, and it may take a health care provider's vision of a future with improved health to engage a patient's hope.

Refugee patients often have had multiple adverse experiences which can accumulate and lead to shorter life expectancy, adoption of unhealthy behaviors and various other impairments. Studies of adverse childhood experiences (Centers for Disease Control and Prevention, n.d.) have given health care providers powerful insight into the lasting harm done by early adversity. Health care providers can share this understanding with refugee patients and help plan for ways to construct healthier lifestyles while addressing the physical and emotional impacts of stress, trauma and torture.





## RECOMMENDATIONS

Understand and be prepared to explain the long terms effects of trauma to refugee patients. Be attuned to somatic complaints that are complicated derivatives of emotional pain, chronic pain, and stress. Offer basic psychoeducation statements about the physical and emotional impacts of stress such as the following:

- It makes sense that you have this symptom. As a survivor of war trauma or persecution, you have developed strong survival skills and some of the symptoms you are experiencing now are related to those skills, including being extra watchful or sometimes shutting down.
- We know experiencing bad experiences during childhood like you experienced have long-term impacts. We often hold stress and traumatic experiences in our bodies, and some of your physical symptoms could be related to these experiences.
- Diet (including hydration), sleep, and exercise are important for managing and improving physical and mental health symptoms. You may not have had good sleep and food during war. I would like to explore ways you could stabilize these health elements.

Directly inquire about adverse childhood experiences. Provide information on why you are inquiring about your patient's childhood experiences and how this information could help you better support their health. Ask questions using supportive and normalizing language, such as, "Often people have experienced difficult experiences as a child and have witnessed or experienced violence in their home. Did you have this experience?" Be aware of adverse childhood experiences that may be more common among certain populations (such as starvation, conscription of child soldiers, human trafficking, and female genital cutting).

### EXAMPLE

A patient from East Africa described blurred vision and shortness of breath to her primary doctor. During the examination, the doctor learned that the patient had survived physical abuse as a child and torture as an adult. The doctor talked with the patient about various steps they would take together to improve her health, such as scheduling an eye appointment and testing for things like allergies and asthma. In addition, the doctor talked with the patient about common physiological responses to long-term trauma, such as feeling panicked and overwhelmed. The doctor suggested that it was important for the patient to spend some time caring for herself through relaxation and social connection because it was important for her long-term health. The doctor described how patients with long-term trauma experiences have benefited from collaborative treatment, including mental health services in consultation with primary care. By normalizing the patient's experiences and symptoms, this patient increased engagement in services, accepted referrals for collaborative care, and reported having an increased sense of hope.



## Past Health Care Experiences

Refugee patients will have different health care experiences than native-born patients in the United States. Their access to health care providers and medicine has likely varied during each stage of the triple-trauma paradigm. The basic way that refugee patients attended to their health in their home culture is rooted deeply in their thoughts, emotions and behaviors, and these perspectives will inform their beliefs and perceptions about what health care should look like in a new country. For instance, some refugees may come from a context in which people only went to hospitals to die, or health care was so ineffective or dangerous it was seen as a last resort. In addition, some refugee cultures have had limited exposure to Western medicine. Often, medications used for short term relief of symptoms were the only ones available, and these medicines might have been antibiotics, pain medications or anti-anxiety medications not intended for long-term use. See chapter 8 for more information and recommendations about medications.



### RECOMMENDATIONS

Ask patients about their previous experiences with health care: in their home country, at the refugee camp or during flight, and since coming to the United States. Ask what they did when they felt sick if they did not have access to formal medical care. Ask about their experience taking medications (and for more information specific to medications see Chapter 8).

## Assess Education and Literacy Level; Tailor Interventions Accordingly

Refugee patients' literacy and education level will impact their health care experience. Differences in educational systems and opportunities across countries, coupled with the timing of when their lives were disrupted, leads to varied experiences in education prior to resettlement in the United States. Also, education may have a completely different meaning (e.g., Koranic school) in contexts where religion colors all aspects of life. Understanding these backgrounds and inquiring about educational opportunities helps health

care providers understand the strengths and limitations of refugee patients as they interact with U.S. systems. Some languages were not written until recently, making issues of spelling and translation far more varied and complicated. Literacy in one's primary language can translate into success with hearing or writing instructions in that primary language; however, pre-literacy in one's primary language could lead to additional barriers in understanding medical recommendations and one's ability to follow through, particularly when memory is a concern.

Knowing the level of language ability and education helps providers determine if additional strategies will be needed for a refugee patient to successfully understand and follow through with their treatment plan. For example, some patients will be very uncomfortable asking questions. Some patients will associate their low education level with a sense of worthlessness and might even feel embarrassed when asked to sign their name, a skill they may never have learned. Some refugees may also have a high level of education that people dismiss due to false assumptions about refugees.

For example, in a sample of resettled refugees from Burma and Thailand receiving treatment in primary care, little formal education was reported among clients. Over half reported no formal education, and mean years of formal education was 2.8 years among the full sample (Center for Victims of Torture, 2018). In contrast, greater formal education was reported among a sample of asylum seekers and refugee clients representing over 40 diverse cultural backgrounds at CVT's St. Paul Healing Center. Approximately 10% of clients reported having no prior formal education, and clients had over 12 years of formal education on average (Center for Victims of Torture, 2017).



### RECOMMENDATIONS

Develop sensitivity and awareness about patients' education level and effective approaches to meet each individual's needs. This topic is discussed in more detail in the following chapter.

## Assess Immigration Status and Family Separation

Common immigration statuses include refugee, asylum seeker, Temporary Protected Status (TPS), student visa status, T visa status (for victims of domestic violence/trafficking), and undocumented. Refugee patients' immigration status may indicate that they are experiencing certain needs or stressors. For example, asylum seekers are not immediately able to work legally and need additional supports to meet their basic needs while in the United States waiting to receive a work permit. Refugee patients will be concerned about their permanent residency status and the process for applying for citizenship after five years in the United States. Traumatic experiences might also influence their memory ability and therefore their success in both acculturating and learning English and civics requirements necessary for passing the U.S. citizenship test. All of these experiences are directly related to how safe and stable a refugee patient feels, and health care providers who are mindful of assisting in these processes, including assessing for waivers from the English and civics exams when appropriate, can mitigate feelings of worry and insecurity.

Additionally, many refugee patients are separated from family members, another significant source of distress. Separation from spouses/partners and children is frequently reported by asylum seekers and refugees receiving care from CVT's St. Paul Healing Center. In 2017, approximately 76% of clients at the St. Paul Healing Center reported experiencing separation from a spouse or partner; and 89% of clients stated they have been separated from one or more of their children prior to resettlement (Center for Victims of Torture, 2017)



## RECOMMENDATIONS

Ask questions regarding immigration status with an awareness that many patients are fearful about the legal implications of their status, including but not limited to the possibility of deportation. Make connections with local legal immigration services that can help refugees understand and advocate for family reunification. Also, when there is family separation, validate and normalize grief, worry, and angry reactions. Finally, the concept of ambiguous loss can be helpful to review, as ambiguous losses often can freeze the grieving process (Boss, 1999).

## Disparities: Race, Gender, Age

Providers need to be aware of the impact of racism, harassment and discrimination on patients, particularly within the health care system. There are persistent health care disparities along racial lines in the U.S. for a number of reasons, including organizational and health care system factors (Fiscella & Sanders, 2017). Too frequently, refugee patients report feeling that their treatment does not seem as valuable as the care offered to a patient native to the United States, for example when they arrive in the emergency room and feel their concerns are not heard or understood.

Refugees encounter identity-related oppression in the United States for which they are often not prepared. Imagine the experience of refugees of African descent. They might be outwardly labeled as "black" and put in the position of confronting what it means to be "black in America." Patients are subjected to our country's deep racial inequalities, without the shared history or early socialization from parents to fully understand and navigate this landscape. Often patients develop their own conceptions of race; the ways they self-identify may or may not be with people of color. This is often a dynamic, evolving process, and health care providers who are attuned to identity development can offer understanding and affirmation of this complexity.

Gender is another aspect of identity with which providers need to engage. Gender difference between the provider



and patient can add layers of complexity that the provider will need to assess to ensure proper care for the patient. For example, perhaps a patient is a woman from rural East Africa and has been raised to believe that she cannot question males in authority. She is unlikely to provide feedback on her care to a male provider. Even affinity within gender identity can require attention with refugee patients. At CVT, a female patient from a Middle Eastern country met with a female psychotherapist and used several sessions to describe how she viewed herself as equal to men in her country. She felt the need to combat American stereotypes of women from her country before moving forward with the therapy process.

Finally, the age of the provider and patient may impact the patient's comfort in being proactive with their health care planning. A young person from Ethiopia may not feel that he or she can tell an older doctor if a treatment is not helpful or if a medication is having side effects for fear of insulting an elder. Similarly, an elder patient may expect a younger interpreter to do most of the talking in an appointment and to complete any follow-up steps for the patient due to the patient's elder status.



## RECOMMENDATIONS

While providers cannot anticipate or mitigate all aspects of identity difference with refugees, you can respectfully attend to identity within the medical setting by regarding each provider-patient-interpreter relationship as a unique constellation of identities that has tremendous implications for assessment, treatment planning and follow-through. The art of not making erroneous implicit assumptions about social identities takes lifelong practice and is best developed through self-awareness, curiosity, tolerance for ambiguity or not-knowing, and ongoing consultation with interpreters and other cultural brokers.

## SUMMARY OF RECOMMENDATIONS

1. Familiarize yourself with common refugee experiences: Know the basics from this chapter, read more about country of your patients, refugee camp conditions, and current refugee and immigrant policies.
2. Ask your patient about current safety beyond the single question "Are you safe?" Ask questions such as, "What scares you about life in the United States?" "Do you feel safe in your apartment?" "Do you feel safe in a car?"
3. Directly ask about past trauma, during war and refugee experiences, but also other adverse childhood experiences.
4. Ask about previous experience with health care, in patients' home country and during the refugee experience. If patients have little or no experience with formal health care, ask what they did when they were sick.
5. Ask (sensitively) about immigration status.
6. Be aware of how race, culture, ethnicity and gender might impact your patient's health care experience and be open to talking about these issues and advocating for your patient in the system.



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## CASE EXAMPLE: RESOLUTION

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After the screener recommended therapy, Paw met with her doctor and agreed to try meeting with a psychotherapist at the clinic named Lisa. We meet them towards the end of one of their early sessions.

**Lisa:** *Thank you for sharing these difficult experiences. I see the bravery and strength it takes. I believe we can help you find a path toward healing, especially now that we understand more about your terrible losses and how that would contribute to feelings of heaviness.*

**Paw:** *I have to be strong and steady my heart so that my family has health now.*

**Lisa:** *I can tell you're very strong. How did you get through these difficult times?*

**Paw:** *It was a blessing from God; I don't know how I made it here.*

**Lisa:** *You also find strength in your religious faith.*

**Paw:** *Yes, I used to be very active in my church in Burma and Thailand but cannot go now because of my headaches and fear of the drumming.*

**Lisa:** *If you'd like, we could include these concerns as part of our healing plan together. You could attend church when you are feeling better.*

**Paw:** *I do not think I will feel better.*

**Lisa:** *I understand; you've been feeling this way for so long time that it's hard to imagine improving. But I'm committed to helping you improve your health.*

**Paw:** *Okay.*

**Lisa:** *How did you access doctors in Burma or Thailand?*

**Paw:** *In Burma, we went to the hospital, but it was far away. In Thailand, we received the medications we needed each day from the doctor in the camp.*

**Lisa:** *I imagine our health system seems very different.*

**Paw:** *Yes, there are so many appointments.*

**Lisa:** *I understand!*

**Paw:** *I don't know what they are all for. Sometimes I go but sometimes I don't because I don't what it means. Who are all of these people? It's confusing.*

**Lisa:** *I'll talk to your providers. We'll work with you to better understand who you're seeing and why. And we'll help you manage these appointments.*

**Paw:** *Thank you.*

**Lisa:** *Aside from going to church, are there other things you would like to do if you were feeling better?*

**Paw:** *I would love to go to school. When I think about school I always smile.*





**Lisa:** *I can see you smiling now.*

**Paw:** *I never went to school because my family needed me to work. My children go to school now.*

**Lisa:** *How does that make you feel?*

**Paw:** *I feel happy. I never went to school but that's not why we came here. We came here so that our children could go to school.*

**Lisa:** *You gave them a wonderful opportunity.*

**Paw:** *I had to. But now I have so much stress. Letters I don't understand, bills, and my children's health and education.*

**Lisa:** *That sounds overwhelming. I can see that would be very hard to manage. Why don't I make a list now to make sure we continue to discuss these concerns and make a plan to help?*

**Paw:** *Okay.*

**Lisa:** *I truly admire your strength. To come to the United States and start a new chapter for yourself and your family. It sounds like you are doing what you can to be successful and healthy. I also appreciate your courage in meeting with me. I look forward to building on these strengths and working with your doctor to help you feel healthier and lighter.*

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## DISCUSSION QUESTIONS

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Following the best practices shared during this chapter and case interactions, consider the following questions to help challenge your learning and integrate these practices into your work.

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*Imagine you are in the position of the patient in this case example.*

- › How safe and secure do you feel and what all goes into this for you?
- › Would you feel comfortable sharing your past experiences with your doctor or psychotherapist? What hesitations would you have? Why?

*Imagine you are in the position of the provider in this case example.*

- › Consider when a patient has shared their trauma history. What helped make that patient feel comfortable? How did you respond?
- › When do you ask about a patient's trauma history? When have you found it appropriate or inappropriate to ask?
- › How do you promote patient resilience?



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# Assessment and Symptom Presentation

## CHAPTER 3

### CASE EXAMPLE

Paw talks to a friend about her health concerns:

*"I often forget what I am doing when I have a headache and my head feels hot. Yesterday, I was cooking food for my husband and children before they came home from work and school, and my head suddenly started hurting really badly, so badly that I couldn't see for a moment. I went to my room to lie down for a bit, and when I woke up, the food I was cooking had burned. I had to throw it away. I was so scared when thinking how the whole apartment could have burned down. I visited my doctor but I don't feel better. I told him about my headache and how my head always feels hot and he gave me some medication to take. I'm supposed to take them only when I'm having headache, so I use them only when the pain is so bad that I can't see. But they don't help. Only for a few minutes. I told my doctor that the medication did not help much. I told him that the pain is so bad that it spreads through my head and neck, and my neck and head always "feel heavy." I answer the same questions over and over again. The interpreter asks me the questions when I make an appointment and then the nurse asks me the same questions when I come for an appointment and then when I see the doctors he asks me the same questions again. Doesn't anyone listen? They write everything down. Don't they read it? Doesn't the doctor already know about my headaches?"*

Paw has established care at the same clinic where she completed her refugee screening. She has met with Dr. Smith, who has very little experience with refugees or interpreters and is new to the clinic. Dr. Smith wants to help Paw improve, but Paw is not feeling better. Paw communicates through a professional Karen interpreter.

**Paw:** *I don't know. Someone picked me up and I am here. The driver told me I have an appointment here, and he dropped me off.*

**MD:** *Let's see here. Let me pull up your chart. It looks like you had some headaches. Are you still having trouble?*

**Paw:** *Yes.*

**MD:** *Is the ibuprofen helping?*

**Paw:** *The -?*

**MD:** *Is the medicine helping?*

**Paw:** *Sometimes it helps when I have a lot of headache. I take two of them and it goes away but comes back again.*

**MD:** *Where is the pain located?*

**Paw:** *All over my head. The headache has spread to my neck now.*



- MD:** *Okay. Is it a sharp concentrated pain or more of a general dull pain?*
- Paw:** *I don't know what that means. It is always a problem and it always has been. I have heavy and light headaches. Sometimes, I lie down when I have a light headache. I only take medication when I have a heavy headache.*
- MD:** *Well, since the ibuprofen doesn't seem to help as much as we would like, I think we should try something else.*
- Paw:** *Yes, that would be helpful for me.*
- MD:** *I'm going to give you something a little stronger. We'll see if that helps. Take it once a day. What pharmacy do you go to?*
- Paw:** *I think by Maryland St.*
- MD:** *You mean CVS?*
- Paw:** *I don't know. I think so.*
- MD:** *Let's look at your chart. It says Walgreens. I will send it there. Any questions about the medication?*
- Paw:** *No. Not yet.*
- MD:** *Interpreter, please help schedule a follow up appointment for three months from now. Nice to meet you, Paw. See you in three months!*
- Paw:** *Thanks, doctor!*

## Introduction

It is not an easy task to understand the health concerns of refugees exposed to war trauma, torture, limited medical access, limited mental health access and few educational resources. Health care providers need to consider many questions: Are patient issues chronic or acute? How much time do I have to try and address this concern? How reliable is this individual in reporting symptoms? Is this individual **acculturating** to the United States and our health care system? Will patients pick up their prescriptions? How will I know if my instructions are adequate? These and many more questions enter into the encounter.

This chapter has two main parts aimed at addressing these questions:

- 1) screening and assessment tools and
- 2) specific symptoms. Health care providers who bring a wide lens to understanding refugee patient concerns are more likely to detect quietly suffering patients whose underlying mental health needs are not being met. Providers need to cultivate both the general awareness and knowledge of common refugee concerns, as well as **dynamic sizing** when working with any individual patient.

## DEFINITIONS

### Acculturation:

The process of adapting to the traits and customs of another culture.

### Dynamic sizing:

A continual process of assessing how a particular patient fits or does not fit into a group's cultural generalizations due to individual or family differences.



## PART 1: ASSESSMENT AND SCREENING TOOLS

Lisa Ide, a physician at CVT, describes her approach for structuring medical appointments:

*I originally trained as an ER doctor. I have learned that a visit to the ER is like an interrogation: "Why are you here?" "Where is your pain?" "When did it start?" barked out rapidly while the ER doctor leans over the patient on a stretcher. Ideally a visit with a survivor of torture is not at all like an interrogation. I usually start by offering tea or coffee, we sit in the exam room and I introduce myself slowly. I take the time to describe what will happen in the visit—talking and questions followed by a physical exam with a weight check on the scale and a blood pressure check. Instead of starting with the chief complaint or HPI (History of Present Illness), I start with the social history and the family history, making conversation along the way. Then I delve into the past medical history before easing into current complaints which may require a link to memories of torture.*

*Some doctors in their busy, regular clinics are reluctant to ask patients if they have been tortured and they have told me that they don't know what to do if a patient gives a positive response. I would answer that doctors ask patients many questions about areas in which we are not experts—a thorough review of systems in any patient can bring up multiple issues requiring further work up and referral. For example, we all ask about cardiac symptoms though most of us do not insert stents or interpret echoes. So, in a primary care setting, after establishing rapport, I would be sure to ask patients who are refugees or asylum seekers if they have been tortured and I would advise being familiar with the resources in your community.*

*And how to ask? I recommend being direct, asking, "Were you ever jailed or detained?" "Were you ever tortured or injured?"*

*I would also be direct about asking about rape or sexual torture having learned that it is extremely common in survivors of torture, both men and women. And again, I would ask directly after gradually getting to the torture history: "Were you raped?" "Did any torture involve your genital area?"*

*When I do a physical exam I am careful to explain each step along the way and also be clear about when I am going to touch a patient. For example, I will clearly say, "This is a stethoscope. It helps me listen to your lungs and your heart. I am going to touch it to your back. Now I am going to touch it to the front of your chest."*

*At the end of a medical intake at CVT, I will often explain to a patient that things will get better. I will take some time to describe how I have worked at CVT for 18 years and I have seen many patients over the years start to feel better. I will explain that it happens gradually and in fits and starts. I will say that sometimes people will start to sleep a little better, then their headaches improve a little. A patient might go to the dentist and tooth pain might improve. That a patient might have an eye exam and get glasses. Then their headaches continue to abate. Then they are able to get outside and walk a little. Then their back pain and body aches might lessen. Then they might start to sleep a little better on a few more nights. I will be sure to thank them for coming and for sharing their story with me.*

(Personal communication, September 16, 2016)



## Address Trauma in the Medical Assessment

When working with people who have survived traumatic experiences, it is common for health care providers to be concerned about triggering or overwhelming a patient by bringing up past traumatic experiences. Unfortunately, this avoidance on the part of providers can contribute to poor health outcomes by not addressing experiences that could be quite relevant to a refugee's care. Furthermore, a recent meta-analysis about trauma probing in research (Jaffe, DiLillo, Hoffman, Haikalis & Dykstra, 2015) suggests that while some immediate psychological distress can occur, the benefits of directly addressing traumatic experiences are viewed positively. A study conducted by CVT found that 68% of refugee patients did not initiate conversations about how war trauma and violence in their country of origin impacted their lives and health, though the majority wanted to learn more about how traumatic experiences are relevant to their health and health care treatment. (Shannon, O'Dougherty, & Mehta, 2012). Patients also stated that they wanted their doctors to be the ones who initiated conversations about trauma they experienced.



## RECOMMENDATIONS

Richard Mollica, M.D. (2007), director of the Harvard Program for Refugee Trauma, recommends the actions below in response to challenges frequently cited by medical providers. While time is at a premium during patient appointments, time spent promoting two-way education between the provider and patient can help you understand and better address the patient's presenting problem.

CHALLENGE	RECOMMENDATIONS
There is not enough time.	Take a few minutes to collect the trauma story in each visit. Most patients can tell the most important parts of the story in 2 or 3 minutes per visit.
I do not know what to do.	Simply listening to the trauma narrative is the first step towards a holistic approach to treatment. You are not expected to do anything other than listen.
The patient will lose control.	Patients almost never lose control. The worst case scenario is that they will cry (which really isn't that bad).
I do not get paid for this.	This is not true. There are codes for billing time listening to the patient.
The patient will not be able to finish their story before the end of the appointment.	Patients use their time wisely. Research has shown that regardless of how long the office visit is, patients and providers will modify their conversation to stay within that time.
This will open up a lot of disturbing stories.	Be emotionally prepared to listen. If a patient doesn't want to tell their story, they won't.
If the patient gets upset, I have to call in behavioral health immediately.	Primary care can treat 80% of traumatized patients.

Source: Adapted from "A new focus on caring for survivors of extreme violence," by Richard Mollica, 2007, *AMA Journal of Ethics*, retrieved from <http://journalofethics.ama-assn.org/2007/10/cprl1-0710.html>

One final note about assessing trauma survivors: Trauma accelerates a person's nervous system. It is inherently overwhelming. Offering too much information can mean that patients will be unable to process it. Be deliberate, slow and purposeful, and repeat information as needed to confirm understanding with trauma survivors.



## Administer Mental Health Screening

In a busy health care environment, time for exhaustive questioning, history taking and rapport building does not often exist, particularly for early exploration of mental health symptoms. Thankfully, culturally sensitive screening tools and assessments have been developed for people from diverse cultures.

Refugees are often screened at a comprehensive medical exam not long after arriving in the United States. While this may seem like an opportune time to screen for depression and trauma symptoms, this examination could also be misleading. With temporary supports in place during this transitional phase, the newfound joys of family reunification, access to medical support, and access to basic resources, refugees may present as happier and healthier than they might actually be during this “honeymoon” period. Mental health concerns often surface when immediate resettlement supports are no longer available and setbacks occur in establishing ongoing social support, financial independence and acculturation.

A medical provider is put in a difficult position of using Western clinical reasoning while treating an individual who does not present or engage with Western medical care like an acculturated Western patient. A refugee will likely not spontaneously offer a physician background information about their past war trauma or torture experience. In a study conducted in a lobby of a suburban primary care clinic in Minnesota, two thirds of interviewed refugees reported they never shared how they were impacted by war or torture in their home country with their providers (Shannon, O'Dougherty, & Mehta, 2012). They reported they wanted to share this information if it was relevant to their health care. Importantly, refugees wanted their health care providers to initiate this conversation, asking about their history and experiences.

### DEFINITIONS

#### *Health literacy:*

*The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions (Centers for Disease Control and Prevention, n.d.).*



## RECOMMENDATIONS

Administer a mental health screening to refugees as part of your initial assessment, as well as at regular intervals (every three months or every six months) to account for the honeymoon period and to monitor adjustment. Keep in mind that the stage of resettlement (see Chapter 2) can affect your assessment. Whether a refugee is most immediately dealing with loss, transition or adaptation will affect the patient's presentation at their appointment.

CVT helped the State of Minnesota to develop a brief screening tool to help ascertain whether or not refugee patients are experiencing mental health problems. These questions were chosen from a larger item pool based on their association with PTSD and depression in refugees, in response to physicians' need for

a short set of questions that work across cultures.<sup>1</sup> The following questions can be used as a brief mental health screening for refugee patients,

- 1) In the past month, have you had many **bad dreams or nightmares** that remind you of things that happened in your country or refugee camp?
- 2) In the past month, have you felt **very sad**?
- 3) In the past month, have you been **thinking too much** about the past (even if you did not want to)?
- 4) In the past month, have you **avoided situations that remind you of the past**? (PROMPT: *Do you turn off the radio or TV if the program is disturbing?*)
- 5) Do any of these problems make it **difficult to do what you need to do on a daily basis**? (PROMPT: *Are you able to take care of yourself and your family?*) (Minnesota Department of Health Refugee Health Program, 2014)

<sup>1</sup>For more information on the project, go to <http://www.health.state.mn.us/divs/idepc/refugee/guide/mhguidelines14.pdf>. Other behavioral health screening tools of various lengths and detail have been implemented in various places in the United States. The Refugee Health Technical Assistance Center offers a discussion and examples: <http://refugeehealthta.org/physical-mental-health/mental-health/adult-mental-health/assessments-for-trauma-and-mental-health-in-refugees/>.



### A Caution on Screening Tools:

*Screening tools that have not been culturally adapted are often used in health care settings. Confusing or offensive questions may be conveyed without cultural adaptations to the tools. For example, CVT clinicians worked closely with CVT interpreters to translate and adapt the Hopkins Symptom Checklist (found at <http://hpvt-cambridge.org/screening/hopkins-symptom-checklist>) depression screener into Karen. The team paid close attention to individual words within the Karen culture during this process and translated the screener back into English. Despite this rigorous process and CVT's many years of specialized experience in cross-cultural work, clinicians became aware of one particularly problematic interpretation after using the screener. When Karen interpreters interpreted the screener question "Have you experienced a loss of sexual interest or pleasure in the last two weeks?" it was interpreted in Karen as interest in multiple sexual partners. Clinicians did not realize how offensive the questioning was until an interpreter brought it to their attention. The team addressed this dilemma by discussing the balance between reliable diagnostic assessment and cultural sensitivity. In the end, the team amended the inventory, omitting the item. This example reinforced the importance of relationship building with both patients and interpreters (discussed more in Chapter 7) to assure quality assessment with the remaining items on the measure.*

### Consider Who Screens

Who administers the screener? Some assessments are self-administered while others are clinician-administered. Results may differ based upon who completes it. Literacy level serves as a barrier in self-administered screeners, even when translated into the patient's primary language. Patients are often unfamiliar with the Likert rating scales commonly used in self-administered screeners. If interpreters administer the screener in the lobby with patients, they may bring their own bias into the explanation of the measure and understanding of the answers. The meaning of each question is now dependent on the skill, understanding and literacy ability of the interpreter. Also, if there are questions about suicide or self-harm in the screener and the patients responds affirmatively, the interpreter in a difficult situation for which they aren't trained (nor it is their role) to handle. In clinician-administered screeners, the demeanor and tone of either the clinician or interpreter may also contribute to inaccurate screener responses. When unaddressed, these factors contribute to significant validity problems.



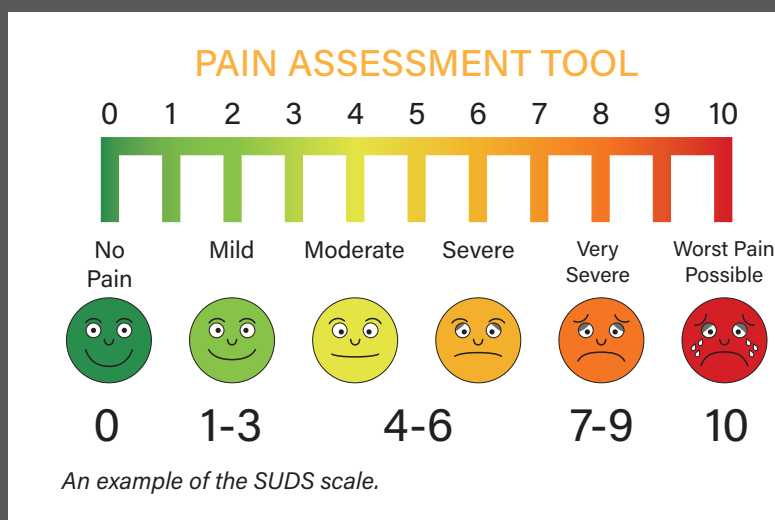
## RECOMMENDATIONS

- Inquire about literacy and education levels in the patient's primary language. Use an interpreter when patients have some command of the English language but are not fluent. Mental health symptoms are often metaphoric and difficult to explain in a second language.
- Be transparent. Take the time to explain why you are asking the questions you are asking. Without transparency, your questions may be perceived as taboo, or you might inadvertently imply that the patient is "crazy." Instead, offer an explanation: "I want to ask you some questions about your thoughts and feelings. I am asking these questions because they are all symptoms that people often experience after living through bad experiences like war."
- Pause, slow down and speak in short sentences that can be easily interpreted and allow for back and forth with the patient.
- When attempting to understand the degree and frequency of symptoms, be aware scales do not always translate well cross-culturally. Alternative references for time/frequency are often needed.
  - › Glasses filled with differing amounts of water can be used to represent severity of a symptom.
  - › Some patients might track history best in reference to the season (e.g., "Did that happen during the rainy season?") or in relation to life events. Consider asking in reference to childbirth, marriage, location where living and other events.
  - › Time of day and functional interference might also help you to understand symptom severity (e.g., "Do you feel that way when you wake up in the morning? Does this pain interfere with your ability to sleep?").

- Utilize culturally appropriate examples to explain symptoms that might be confusing. Notice when a patient might be using an idiomatic or metaphoric expression of distress.
- Remember that health care providers (doctors, teachers, nurses) are often respected in a refugee patient's culture, or worse, feared (in some countries, doctors participate in interrogation sessions, falsification of records, or wrongful medical treatment/deprivation). Refugee patients may be hesitant to tell the provider they do not understand a question related to a mental health symptom or do not understand how to answer based on a scale. If you sense hesitancy, ask the question in a different way or offer a concrete example.

### EXAMPLE

Some patients find the faces on SUDS scales confusing, particularly if they are in color (red to green). Not all facial expressions mean the same things in each culture (e.g., a broad smile). One patient told a provider that the red face on a SUDS scale looked like a fruit and she couldn't connect the face to her experience of pain.



## Determine Patient Understanding of the Problem

Jumping too quickly to problem solving can undermine the **self-efficacy** of patients, particularly refugee patients who are not accustomed to the U.S. health care system. Exploration and understanding, when appropriate, can enhance engagement and increase trust between patients and their providers. Providers need to enter into conversations with patients with curiosity about their full experience to help patients feel supported and understood.

### DEFINITIONS

#### **Self-efficacy:**

*One's belief that she or he can accomplish a specific goal or task.*

How does the patient understand or explain the reason for their symptoms and problems? What are their beliefs about the origin of their pain or sickness, and what are their beliefs about what is needed to get better? Obtaining this information is key to understanding what a patient might be expecting and can offer insight into whether they may agree with an assessment and treatment plan.



## RECOMMENDATIONS

Kleinman and Benson (2006) recommends posing the following questions to help providers better understand symptoms and expectations for treatment from the patient's perspective:

- 1) What do you call the problem?
- 2) What do you think has caused the problem?
- 3) Why do you think it started when it did?
- 4) What do you think the sickness does? How does it work?
- 5) How severe is the sickness? Will it have a short or long course?
- 6) What kind of treatment do you think the patient should receive? What are the most important results you hope she receives from this treatment?
- 7) What are the chief problems the sickness has caused?
- 8) What do you fear most about the sickness?

Additionally, providers can ask if the patient knows others with this problem or illness. If so, where? Was the person in their country of origin and what happened with their illness? Is the person in the United States, and how is the illness cared for? This conversation can reveal important expectations or worries the patient has related to their symptoms and treatment<sup>2</sup>

## *Be Aware of Cross-Cultural Communication in Assessment*

The Western medical model depends on patients identifying problems with their health and telling them directly to their providers. Patients usually are responsible for following up with their providers regarding the progress of treatment and informing providers of any issues that arise. These communication norms are not consistent across cultures. Refugees often come from countries that employ tactics such as torture to control and silence their populations. For some refugees, doctors were among the perpetrators who designed and carried out torture techniques. Refugees might not speak out, question or complain, particularly to people they perceive as authorities, including medical providers. These experiences, in combination with specific cultural norms of communication, highlight the need for providers to be aware of patient communication style. This awareness enhances providers' ability to effectively increase patient engagement, especially in treatment planning and follow through.

<sup>2</sup> Another tool for assessing patient perspective the cause and solution for problems is the Cultural Formulation Interview (CFI) from the American Psychiatric Association, found here: [https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwiK8fSO667TAhXHLmMKHezPD80QFggpMAA&url=https%3A%2F%2Fwww.psychiatry.org%2FFile%2520Library%2FPsychiatrists%2FPractice%2FDSM%2FAPA\\_DSM5\\_Cultural-Formulation-Interview.pdf&usq=AFQjCNELEKr7I88QBIOEn0mVxKI5OLGbg&sig2=W0jS1d1zmbmpRWvmQuMfew&cad=rja](https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwiK8fSO667TAhXHLmMKHezPD80QFggpMAA&url=https%3A%2F%2Fwww.psychiatry.org%2FFile%2520Library%2FPsychiatrists%2FPractice%2FDSM%2FAPA_DSM5_Cultural-Formulation-Interview.pdf&usq=AFQjCNELEKr7I88QBIOEn0mVxKI5OLGbg&sig2=W0jS1d1zmbmpRWvmQuMfew&cad=rja).





## RECOMMENDATIONS

Try to ascertain the following information about your patient's culture(s):

- Is this culture high or low context in communication? In high context cultures, the rules of communication (content, terms, verb tense, tone, nonverbal behavior) are differentiated based on whom you are talking to (gender, age, social status, etc.) and who you are in relationship to this person. With the United States being a low context culture, many miss this complexity.
- Does the culture have a nonverbal communication style? What can you learn from gestures and facial expressions? For example, if your patient commonly sucks in his breath or raises his eyebrow in response to a question, it might be helpful to know whether this is a cultural expression of agreement or emphasis, or whether this is an individual response pattern with a different meaning. How will my own gestures and facial expressions be received?
- Does the culture rely on written communication? Should I provide things in writing? Are oral instructions more common? Could visual representations be helpful?
- Does this culture practice a direct or indirect communication style? How might my communication style be received?

### EXAMPLE

*Ah Na* is a Karen cultural norm understood by Westerners as a nonconfrontational demeanor and deference to others, including health care providers. Some Karen describe *Ah Na* as a sense of deference and not wanting to impose upon the people in their lives. While this cultural expression can happen between peers, it can also happen with a health care provider. At times, it can be seen in the simple expression such as, "No, I don't have any questions"—even when the patient might be confused or have quite a bit to say about a topic. Gentle probing and expressing interest in the patient saying more can be helpful, especially when accompanied by an explanation of the value of learning more from the patient.

Additional hesitation coming from *Ah Na* occurs when Karen patients interact with a "teacher," or an individual of perceived higher social standing. This hesitation can come with an expectation that a person of perceived higher status will know what is best for this Karen individual. It is unlikely that a Karen patient will correct their provider, ask a question, ask for help, or express any tone of disagreement. Western health care providers need to understand this dynamic and find ways to work effectively when assessing symptoms, including change of symptoms over time.

## *Determine Health Literacy*

Education and health literacy are not the same concept, and health literacy in one culture might not readily transfer to health literacy in another culture. Norms for treatment adherence and understanding of medical terms and diagnoses can vary significantly from culture to culture, group to group and person to person. In the health care setting, it is essential to develop a shared understanding between the provider and patient of the problem and its treatment.



### **RECOMMENDATIONS**

Your skill as an educator is vital. One method for creating opportunities to determine a patient's health literacy and ability to follow a recommended treatment plan is to offer an explicit description of the disease or problem, rationale for treatment approaches, and opportunities for the patient to share their understanding of their problem and the treatment with you. For example, does the patient only take medication when feeling badly, or double it when feeling worse? This approach helps to reveal differences in beliefs or values while also assessing health literacy shortcomings that might hamper effective treatment. See chapter 4 for more information.

## *Validate During Assessment*

Refugee patients with somatic pain often report feeling resigned and confused about their condition. Patients feel frustrated if lab results or tests come back "normal" when their experiences of pain are far from normal. One patient shared a desire for providers to have a machine that would show her doctor her pain so she could be believed. The need to be understood and validated in one's experience is universal.



### **RECOMMENDATIONS**

Utilize different strategies when assessing symptoms to validate the refugee patient's experience. Explaining ways in which emotional health and physical health overlap with one another can be powerfully destigmatizing and validating when coming from a medical professional.

## *Assess the Whole Picture*

The individual appointment should not be the sole source of information about a patient and their problems. Refugee patients will not always bring up their concerns in a way that Western medical providers will readily understand.





## RECOMMENDATIONS

Thoroughly review a patient's medical record for multiple visits to address a similar problem. A chronic problem, the root cause of more superficial problems, a patient's lack of understanding the treatment plan, hidden mental health concerns, or other obstacles to successful treatment may come to light in such a review. With the fast pace required in many medical settings, it can be the norm to offer specific guidance on one problem each visit. But refugee patients who are not offered descriptions of their current concern while coordinating with treatments for other concerns can feel confused and unable to successfully follow their treatment plan. Address health concerns holistically, consider cultural differences, understand norms established around suffering and deprivation, and explore cross-cultural and cross-language difficulties.

### EXAMPLE

Dizziness is a common way for many Karen patients to describe poor health. A Western understanding of dizziness might lead a provider to consider diagnoses such as ear infection, allergy, anemia and other associated concerns; however, this term and expression can also describe experiences of depression, anxiety and emotional overwhelm, in addition to dietary insufficiencies. When providers can inquire with greater specificity and with a trauma-informed lens, this wider spectrum of concerns can be addressed.

### *Examine Discrepant Pieces of Information*

Given refugee patients' use of indirect or nonverbal communication and idiomatic expressions, lack of health literacy, and other issues, it can be common for individual providers to hear statements from refugee patients that might come across as contradictory. Fortunately, strong communication across a care team, as well as an open-minded attitude towards understanding these expressions, can help in these situations. With Paw's example, one can imagine that any individual piece of her experience that is shared most prominently could color a health care provider's decision-making process about her health care needs.



## RECOMMENDATIONS

Seek informed consent from patients for providers to consult, with care given to explaining what information is to be shared and for what reason. When this sharing takes place, providers understand a more complete picture of the obstacles related to physical health, mental health and poverty that might be part of the patient's presentation. Of course, it is possible for individual providers to come to different conclusions based on the same patient content and presentation. With use of dynamic sizing, comparison of information between providers where informed consent has been obtained, clinical hypothesis testing accompanied by explanation, and use of tools such as the Cultural Formulation Interview (APA, 2013), providers can collaborate to determine helpful treatment strategies and enhance meaningful patient engagement.



## PART 2: SYMPTOM PRESENTATION

*This section offers information and recommendations about how to assess certain symptoms and clusters of symptoms that may be raised by a refugee patient.*

### Somatic Symptoms

Many refugees will present with obvious and significant physical sequelae related to their war, torture and flight experience. Other times there may be no physical findings for serious physical symptoms presented by refugees. Refugees may present their problems as somatic complaints (symptoms the patient is experiencing but that can't be fully explained as a medical problem) for some of the following reasons:

- They have untreated physical problems due to lack of access to adequate health care in the country of origin or refugee camp.
- Experiences of depression and trauma have many physical manifestations.
- Identifying emotional or cognitive concerns may be a foreign concept.
- Mental health may be stigmatized or understood as "crazy."
- There may be little to no mental health infrastructure in the client's country of origin, therefore little structure for talking about mental health.
- Health literacy limitations might keep a refugee patient from describing problems in a way Western health care providers readily understand.
- Identifying somatic problems may be a culturally congruent way of describing emotional pain.
- Treatment options understood by refugee patients may only include medicines used for the limited options (e.g., pain, blood pressure, infections) available in other settings.
- Idioms of distress from a refugee's culture might not be readily understood by those from another culture.

symptoms of these diagnoses helps with differential diagnoses for somatic and mental health concerns. See this list of common somatic concerns that could be involved in a patient's presentation of MDD or PTSD:

- |  |   |
|--|---|
| ▪ Fatigue/Tired  | ▪ Profuse sweating                      |
| ▪ Irritability   | ▪ Ringing in ears                       |
| ▪ Hypersomnia (sleeping too much)                                      | ▪ Constipation                          |
| ▪ Memory difficulty  | ▪ Blurry vision                         |
| ▪ Insomnia (sleeping too little; patients might say, "I don't sleep.") | ▪ Diarrhea                              |
| ▪ Dizziness  | ▪ Muscle pain                           |
| ▪ High blood pressure  | ▪ Gastritis/difficulties with digestion |
| ▪ Feeling weak   | ▪ Nerve pain                            |
| ▪ Stomach pain   | ▪ Shortness of breath                   |
| ▪ Hot/cold sensation   | ▪ Headache                              |
|  | ▪ Back pain                             |
|  | ▪ Chest pain                            |

While this list is not exhaustive, presentation of these symptoms could serve as a flag for further inquiry about patients' experiences of war, torture, loss, fear and deprivation. Often health care providers run tests and provide treatment, yet the symptoms persist after multiple interventions. This may indicate a mental health concern is present.

For refugees coming from cultural groups that have experienced war trauma and torture, rates of Major Depressive Disorder (MDD), anxiety disorders and trauma disorders such as Post-Traumatic Stress Disorder are high (Bogic, Njoku, & Priebe, 2015). Knowing the common





## RECOMMENDATIONS

Sometimes physical and mental health symptoms are independent—for example when a headache is just a headache. It is important to not over diagnose or pathologize refugee patient symptoms, but it is equally important for medical providers to use trauma-informed and mental health lenses. Don't initially assume a refugee's symptoms are somatic; complete a full diagnostic work up as you would for any patient experiencing the same problem.

If results come back negative or when somatic complaints are difficult to understand, don't tell a refugee patient that there is nothing wrong with them or that their pain is not real. This will only invalidate a patient's felt experience of the pain. Listen and believe. If you suspect the pain is psychological in nature, offer education about how stress and worry and sadness can make pain worse. Consider a brief consultation with a mental health provider, or a referral for a mental health assessment or pain clinic, and debrief with an interpreter to understand language and cultural issues that may inflect these conversations.

Similarly, consider if a physical condition could be causing symptoms that arise for patients. It is easy to become so narrowly focused on a patient's mental health treatment that physical health symptoms are not recognized as independent medical illnesses (Morrison, 2014).

### *Idioms of Distress*

There are many cultural differences in the expression of physical and psychological distress. Western psychological terms are often quite foreign to refugees, and terms such as depression and anxiety are not easily translated into many languages. Among refugee groups, there are different ways individuals understand and explain their suffering to others, including medical providers. Idioms of distress include language, behaviors, and symbolic expressions that explain or describe experiences of suffering that are unique to a particular cultural group. Idioms of distress are influenced by cultural beliefs, social and historical factors, experiences of war and trauma, and daily life and social stressors related to migration and resettlement.

Some examples of idioms of distress are as follows:

- "Heavy heart" in Karen people from Burma.
- "Wind attacks" or "being hit by the wind" in Cambodian culture.
- "Nerve attacks" in Latino/a cultures.
- "Air in the brain" in Somali culture.
- "Burning from the inside" in Oromo culture.





## RECOMMENDATIONS

- Listen for descriptions of physical and psychological distress that might be idiomatic in nature. It may be a somatic description of symptoms or sensations in the body.
- Idioms are helpful in making differential diagnoses. A refugee patient may arrive complaining of “heart pain” or “neck pain” that may be idiomatic in nature. Naturally, a health care provider will worry about heart disease or heart attack in these situations. Ask follow up questions about the origin of the problem and other symptoms that are connected to determine the best course of treatment.
- Recognizing an idiom of distress can help build connection and rapport with a refugee patient. It shows competency, empathy and a desire to understand the patient’s problem.
- Idioms of distress are helpful in assessing for psychological disorders. It is impossible to develop an assessment tool for people of every culture that come to the clinic, and every culture is constantly changing internally. Moreover, providers are often required to use certain screening tools or assessment measures that are approved by the clinic where they work. Listening for idioms of distress can help a provider with quality assessment. Providers can use idioms when giving examples of assessment questions. They can also listen for patients to describe an idiom, and use that to ask more questions for a description of the problem.
- Using idioms of distress is useful in framing mental health services and psychotropic medication treatment. Many refugee patients have never experienced mental health treatment before, or the concept has been highly stigmatized. Using an idiom of distress can be helpful in developing a shared understanding (for example, “This is your therapist. His job is to help you with your heavy heart,” or “This medication is an antidepressant. That means it may help you with the heavy or tired feelings you have in your heart.”).

### EXAMPLE 1

At CVT, providers have heard many Oromo patients describe that a part of the body is out of their control, such as, “My arm is not mine. I cannot control it.” One patient had many expensive neurological tests done without an explanation for this arm condition. After consultation with the interpreter, the social worker learned that this was an expression of dissociation from the body due to a trauma experience. The patient had experienced torture involving that arm. Feeling a full sense of connection to her arm caused her to have distressing memories of her torture.



## EXAMPLE 2

Karen refugees often use terminology related to the heart to indicate distress and emotional content. Phrases such as “heavy heart” or *tha hkuh* are often related to an experience Westerners might conceptualize as sadness. Descriptions like these may have just as much to say about emotional experiences as physical health experiences. A connection between temperature changes and *tha hkuh* (“heavy heart”) was expressed by 24% (22 of 92) of Karen refugees interviewed about cultural concepts of distress. A hot, burning heart was described in relation to experiencing intense emotions stemming from traumatic events they or their family members had survived pre- or post-flight from war in Burma. In contrast, feeling cold was described when experiencing fatigue and the desire to be alone. Karen refugee interviewees also stated that “cleaning of the heart” from “dirt” or “darkness” served as a way to remove worry, shame or sadness. For instance, a woman in her late 50s explained, “Sometimes when I am thinking too much about the feelings in my heart, I want to take out my heart outside and I want to clean my heart of darkness and put it back in.”

These expressions of distress are worthy of further inquiry from health care providers. Unfortunately, this follow up inquiry has not been standard, and many Karen people who have complained of heart-related problems have come away from medical appointments with antacid medications and other treatments that do not best address an emotional experience.

## Fatigue

For patients with MDD, PTSD and/or chronic pain, fatigue is often also present. Ongoing fatigue contributes to a lack of motivation, including motivation to engage in healthy behaviors. Trouble sleeping, poor appetite and sedentary lifestyle habits may also be contributing factors to low energy and require further assessment.



## RECOMMENDATIONS

Ask detailed questions about patients’ sleep habits, including quality and quantity. Due to limited understanding of the importance of restful sleep, late work shifts, busy schedules and/or normative experiences of great distress, a refugee patient might not indicate any difficulty with their sleep. A detailed review of sleep hygiene practices, probing for the patient’s routines with each practice, offers great insight into sleep challenges severely impacting a patient’s energy level.

## Memory Problems

People with PTSD are more likely to have memory trouble and difficulty learning new information (Gil et al., 1990). Patients may have a hard time providing details about their symptoms and offering information about potential causes or solutions. In focus groups conducted with four refugee populations (Somali, Oromo, Bhutanese and Karen), participants cited a number of cognitive problems including, short- and long-term memory loss, confusion, and poor concentration (Shannon et al., 2014). For example, Karen patients with MDD often responded with “I don’t know” when asked seemingly straightforward questions from a Western medical or mental health perspective. Patients frequently forget about appointments or follow-up actions they agreed to during an appointment due to memory trouble. Patients may also forget important paperwork for providers, which increases stress for patients. How memory impacts medication adherence is discussed further in Chapter 8. Patients’ perceptions of their memory, age, functioning, and ability matters. Patients frequently describe their memory as “bad” or “not good like before.” A patient might cite old age and coinciding memory difficulty as reason to give up their family or community role, and “old age” might be reached at a very different age in the patient’s culture compared to the host culture.



### RECOMMENDATIONS

Assess memory functioning with respect to common daily tasks in the patient’s life. For example, one patient who complained of poor memory regarding medications and appointments also noted, “I cannot stop remembering what I am stressed or worried about.” Treatment for this patient regarding memory functioning would need to address stress, anxiety and possible depression as a way to improve her memory. Offer psychoeducation about the many ways that memory can be negatively impacted by various refugee experiences.

## Traumatic Brain Injury

Literature suggests a strong relationship between traumatic brain injury (TBI) and PTSD (Bryant, 2011). Many refugees have survived experiences of war or torture such as beatings, falling out of trees, losing consciousness, being exposed to nearby artillery fire and other dangerous situations.



### RECOMMENDATIONS

Inquiring further about head injuries can be valuable. Ask, “Have you experienced assault or injury to your head or senses, such as beatings, falls or explosions?” If a patient has experienced loss of consciousness, ask, “How long were you unconscious? Where were you when you woke up?” Consider augmenting treatment with memory aids that can assist patients in following their treatment plan. Consider further referral for specialists in assessing and treating TBIs, such as a neuropsychologist or occupational therapist. When such referrals are made, don’t assume the specialist has experience working with refugees. Consult prior to the appointment about the patient’s background information (with patient consent).

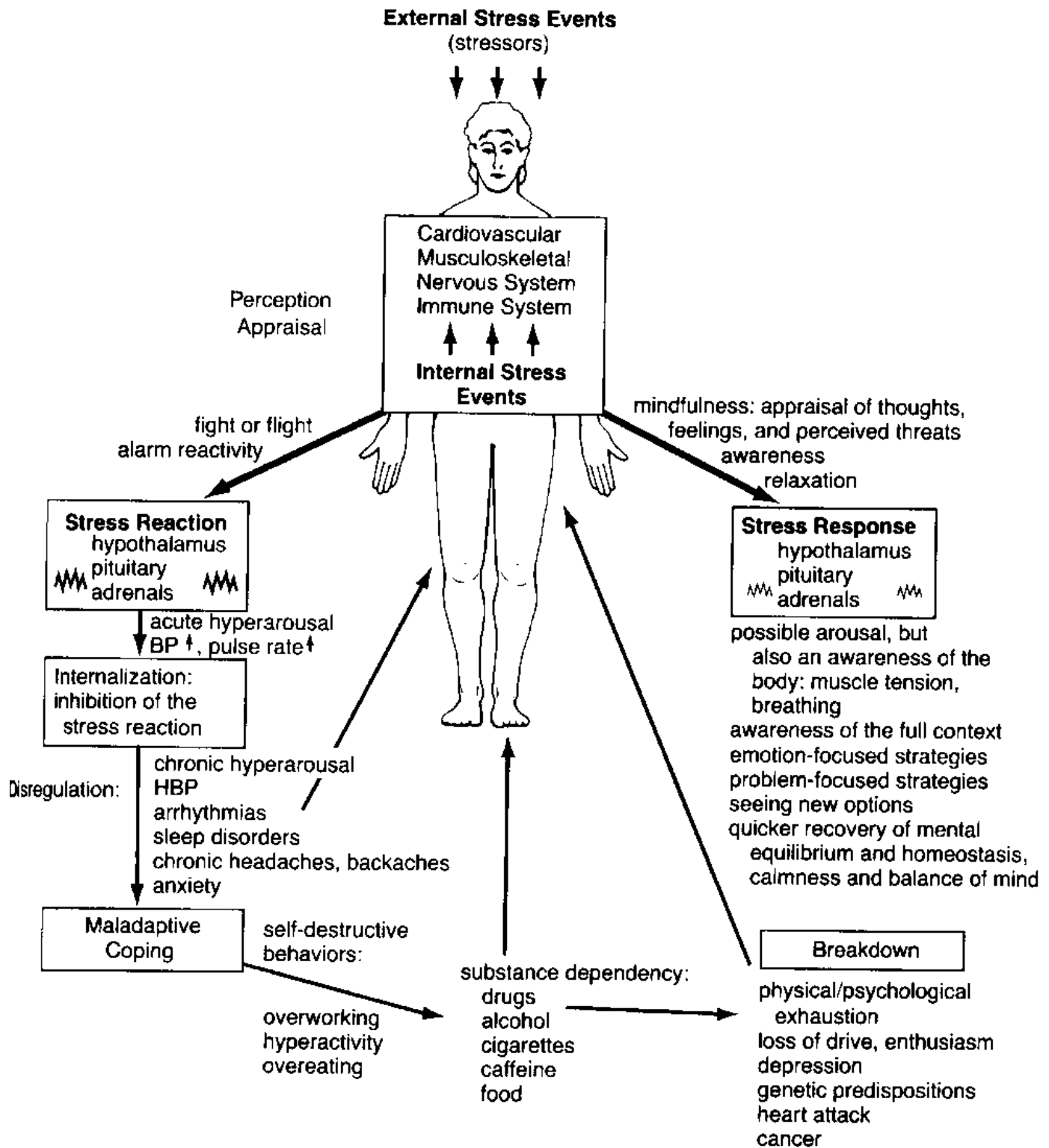
## Chronic Stress

Refugees often experience stress for prolonged periods of time. War, extended periods of time in displacement, and resettlement stressors all contribute to this experience. Refugees may continue to experience considerable stress in their everyday lives after resettlement (see Chapter 5). Internal automatic reactions to stress can exacerbate the stress experienced. Over a long period of time, chronic stress increases the risk of illness and eventual breakdown, as demonstrated below in the stress-reaction chart.



### RECOMMENDATIONS

Include an assessment of past and current stressors to help understand how stress may be impacting a patient’s symptoms and functioning.



Graphic: "External Stress Events" from *FULL CATASTROPHE LIVING* by Jon Kabat-Zinn, copyright © 1990 by Jon Kabat-Zinn. Used by permission of Dell Publishing, an imprint of Random House, a division of Penguin Random House LLC. All rights reserved.



## Psychosis

Refugee patients may present with symptoms that would be classified as psychotic in Western diagnostic manuals. Visual or auditory hallucinations can be misunderstood cross culturally for various reasons, including differences in expression of grief, trauma, relating with ancestors and religious experiences. For example, when working with Karen patients providers found it is common for Karen individuals to describe seeing dark shadows, to feel the presence of a dark figure, or to hear voices calling their name. While these experiences could be associated with psychotic symptoms, they were often better understood as culturally congruent experiences. Expression of such experiences is common for Karen individuals when feeling particularly emotionally overwhelmed or reacting to extensive trauma exposure. Mental health providers often determined these experiences were not indications of a psychotic disorder after exploring this expression and its cultural context.



### RECOMMENDATIONS

Learn what experiences are culturally congruent for a refugee patient before assuming or making a psychosis diagnosis. Consider whether their symptoms are tied to their trauma experiences. When a patient is distressed by these symptoms, assess further and refer to psychiatry as indicated. If psychiatry is not readily available, consult with other medical professionals with expertise in refugee mental health.

#### EXAMPLE

Torture survivors across cultures often describe hearing voices or seeing images that (without further assessment) could be construed as psychosis. Often, when reviewed further, these images or voices are directly related to experiences the patient had during an episode of torture.

## Complicated Grief

For many refugees, sudden and violent losses of loved ones during repression, targeted violence or war can result in complicated grief. This form of grieving often does not resolve on its own and often co-exists with other major life stressors. Higson-Smith (2014) argues for consideration of complicated grief as its own distinct diagnosis that needs to be part of the assessment and treatment of refugee groups.



### RECOMMENDATIONS

Assess grief and loss when meeting with refugees. Higson-Smith (2014) recommends inquiring about recent and violent losses and incorporating attending to loss into the treatment plan.

## Eye Pain

For torture survivors, damage to the eyes is sometimes part of the torture. Clients have described being forced to stare at the sun for long periods of time, being beaten around the eyes or having objects inserted into the eyes. A survivor may become quite afraid at an eye appointment with instruments in a dark room. Even for refugees who have not experienced eye torture, many had limited eye care when living in refugee camps. After resettlement, refugees may have access to eye care for the first time. It can be challenging for refugees to effectively communicate with eye care professionals due to the language barrier, appointment logistics and vision tests that have not been validated across cultures. These challenges lead to limited use of eyewear that effectively meets patients' needs. Problems such as nearsightedness, farsightedness, astigmatism and cataracts are not well understood cross-culturally.



### RECOMMENDATIONS

Knowing the educational level of patients and assessing their ability to effectively and knowledgeably engage with eye care professionals is advised. If you know your patient has survived eye trauma, consult with the eye care professional prior to the appointment (with patient's permission) so they can be aware of potential fear and explain each step of the process during the appointment.

## Dental Symptoms

Like the eyes, the teeth are frequently targeted during torture. Many survivors have had teeth forcibly removed or broken during their torture experience. In addition, many refugees have had limited ability to receive adequate dental care. Furthermore, extensive dental work that Western dental providers might recommend can feel overwhelming and confusing, as well as costly.



### RECOMMENDATIONS

Clear explanations about the role dental health can play in overall health and mental health are essential.

- Learn about patients' cleaning practices. With lack of dental hygiene products and education, refugees have reported cleaning their teeth with charcoal, a stick, or salt. Encourage patients to share their cleaning practices with their dentist.
- Offer explanations of dental cleaning habits available in a Western context. Instruct patients to brush teeth twice per day with toothpaste. Let patients know they can drink faucet water (if that is indeed the case in your location), and that it is better for your teeth than bottled water. Refugee experiences with unsafe water in camps mean refugees often assume buying bottled water or boiling water is necessary.
- Discuss healthy eating habits, including nutrition strategies when patients are limited by soft food options.
- Explain connections with poor dental health that come from tobacco, alcohol and drug use, or chewing traditional leaves or seeds, including chat or betel nut.
- Provide comprehensive information regarding benefits and risks of dental procedures to help patients make informed choices.
- Understand the services provided at local dental clinics that accommodate the patient's insurance. Frequently low-cost clinics extract teeth, since more expensive treatments like fillings or crowns are not affordable for clients or covered by insurance.

## Substance Use

Refugees, like the general population, may under-report substance use when answering general questions regarding use. Substance use may also be defined differently across cultures. For example, we found when asking Karen refugees about alcohol use that alcohol was culturally defined as hard liquor. A patient who drinks beer daily would potentially deny any alcohol use if not questioned directly about beer consumption. Furthermore, substances used commonly in a given culture, such as betel nut (a reddish nut ground into a paste and chewed that has a caffeine-like effect and can stain teeth) in Karen culture, can be viewed as both a coping strategy and a dangerous substance that causes tooth decay, gum disease, cancers and pregnancy concerns. Sensitively inquire about use of such substances to determine ways that its use is related to any health concerns.



## RECOMMENDATIONS

It is necessary for providers to be aware of how substance use is perceived culturally and if there is associated stigma. Providers need to explain the nature and purpose of the substance use assessment, normalizing use without judgment and reminding patients about confidentiality of reporting. As you assess substance use, it is important to inquire about prescribed medications that can lead to substance abuse. Many refugees believe that if a doctor prescribes a medication it cannot lead to addiction.

## SUMMARY OF RECOMMENDATIONS

- Ask about trauma. See recommendations in chapter from Mollica (2007) at the Harvard Program for Refugee Trauma for ways to overcome common challenges.
- Use mental health screeners at the initial appointment and then at regular intervals. Here is an example of a brief tool used currently in the state of Minnesota:
  - 1) In the past month, have you had many **bad dreams or nightmares** that remind you of things that happened in your country or refugee camp?
  - 2) In the past month, have you felt **very sad**?
  - 3) In the past month, have you been **thinking too much** about the past (even if you did not want to)?
  - 4) In the past month, have you **avoided situations that remind you of the past**? (*PROMPT: Do you turn off the radio or TV if the program is disturbing?*)
  - 5) Do any of these problems make it **difficult to do what you need to do on a daily basis**? (*PROMPT: Are you able to take care of yourself and your family?*) (Minnesota Department of Health Refugee Health Program, 2014)
- In your assessment of a refugee patient, ask how *they* understand their symptoms.
- Factor a patient's level of acculturation and health literacy into your assessment. Gather information from multiple sources.
- The following symptoms are commonly reported by refugee war survivors: somatic pain, fatigue, memory problems, traumatic brain injury, chronic stress, psychosis, complicated grief, eye and dental pain, and substance use. It is important to understand these symptoms through a lens of their past war experiences and subsequent flight. These symptoms may also be expressed through cultural idioms of distress.



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## CASE EXAMPLE: RESOLUTION

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Paw is attending yet another primary care appointment to address unresolved headaches, her head feeling hot and her head and neck feeling heavy. Because Dr. Smith is at a medical conference learning about cross cultural communication, Paw is seeing Dr. Green today. Dr. Green has integrated some of the practices discussed in this chapter into his medical practice with patients like Paw. Paw talks with Dr. Green with help from a professional Karen interpreter.

**MD:** *Good to see you today, Paw! My name is Dr. Green and I will be helping you today since Dr. Smith is not available. What do you call the problem you're experiencing that brings you here today?*

**Paw:** *My head gets hot and I have headache.*

**MD:** *Your head gets hot and it hurts. Do you have any idea what causes this problem?*

**Paw:** *I have this problem for a long time. It never gets fixed.*

**MD:** *Are any experiences from Burma or Thailand related to this problem?*

**Paw:** *It started after my baby died.*

**MD:** *I am so sorry to hear about your loss. Losing a child is one of the worst things that can happen.*

**Paw:** *We needed to run, so I didn't even get the chance to bury her. I think of her often and I get so angry when thinking about the soldiers. I want to forget.*

**MD:** *I wonder if this anger and sadness contribute to your headaches and feelings of heat and heaviness in your head and neck?*

**Paw:** *It happens like that.*

**MD:** *What kind of treatment do you believe will help with these concerns?*

**Paw:** *I want something to help my headache and heat in my head go away.*

**MD:** *I see that you have tried Tylenol, but we know that Tylenol only helps for a few hours.*

**Paw:** *The headache was only gone a few minutes.*

**MD:** *And Dr. Smith prescribed Naxopen?*

**Paw:** *What is that? I never tried that. My niece picked it up but I didn't understand the directions.*

**MD:** *It's a medicine called naproxen sodium. I think this medicine could help. It lasts for 12 hours, so it will offer help for most of the day*

**Paw:** *That would be helpful.*

**MD:** *Okay. It says here that you're also seeing Lisa, the therapist. How is that going?*



- Paw:** *We just talk. I don't understand how that is going to help.*
- MD:** *Lisa has talked with many Karen people, like you, who have lost children and are grieving and feel anger from bad experiences. Lisa can help you understand the problems that affect your heart and body, like heaviness and pain. She can actually help heal problems that affect body and heart.*
- Paw:** *It's hard. I don't have much time. And I don't have a way to get here.*
- MD:** *Yes, I can understand how it might feel like a lot to have another appointment, but I do think it might help with your headaches. We can help arrange things like transportation and an interpreter because I know that's a problem.*
- Paw:** *Can this really help with my headache?*
- MD:** *Yes. We know that people coming to the United States from Burma and Thailand have lived through many difficult experiences, and adjusting to life here is incredibly difficult. Headaches and other pain can be affected by anger, sadness, worry and stress. Lisa can help you find ways to manage these problems and this transition. Lisa and I will work together to help you.*
- Paw:** *If you think it will help me, I will continue to go.*
- MD:** *Thank you for being open to this. I will send the prescription for the new medicine to your pharmacy. Will anything keep you from picking up and using this medicine?*
- Paw:** *My niece can pick it up for me tomorrow.*
- MD:** *Great. Remember, when you have a headache take one of these pills. Wait 12 hours before taking it again if your headache is still there. If you don't have a headache you don't need to take it. Could you tell me how you will use it?*
- Paw:** *I can take one each day when I have a headache.*
- MD:** *Yes, wait 12 hours before using it again if you are still having headache. Do you have any other questions about this medication?*
- Paw:** *No. I understand.*
- MD:** *Please bring this medicine to our next appointment, and we will review how it helps you. I want to meet with you in three months. Please schedule that at the reception desk.*
- Paw:** *Thank you so much, doctor, for your help.*
- MD:** *So good to meet with you. I will see you in three months.*



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## DISCUSSION QUESTIONS

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Compare the two different interactions showcased in the case examples at the beginning and ending of this chapter. Review the recommendations, and consider these questions to help deepen your learning and prepare for improvements in your practice.

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*Imagine you are in the position of the patient in this case study.*

- › What hesitations might come up for you when discussing your concerns with your physician?
- › What would you want to know about the physician's referral to mental health?
- › What would make you more or less likely to follow through on the referral?

*Imagine you are in the position of the provider in this case study.*

- › How do you decide when a mental health referral would be appropriate?
- › Reflecting on past experience, what makes a successful referral?
- › What strategies do you implement to increase two-way education between the provider and patient regarding their symptoms?

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# Treatment Planning

## CHAPTER 4

### CASE EXAMPLE

With Paw's permission, Lisa (Paw's psychotherapist) contributes to a shared treatment plan documented in the electronic health record. Lisa identifies social service needs, personal strengths, religious preferences and areas Paw has prioritized. With the shared treatment plan, Paw's primary care physician, Dr. Green, is now in a better position to address her health care needs by managing acute symptoms while identifying chronic concerns that also impact her health and quality of life.

**MD:** *Good to see you again, Paw!*

**Paw:** *Good afternoon, doctor.*

**MD:** *I understand you're visiting today because you feel dizzy quite often.*

**Paw:** *Yes, I take the medicine you gave me for my headache, but it does not help with my dizziness.*

**MD:** *Did you bring this medicine to today's appointment?*

**Paw:** *I forgot it at home.*

**MD:** *I see. That's okay, but I think it'll be helpful at future appointments to bring all of your medicine with you. That way we can review your medicines each time. We can see if you're having any trouble following through with our treatment plan, or if the direction on the medicine is confusing to you. If you have questions I can answer them right here. I want to make it easier for you to improve your health. Now, let's discuss more about this dizziness you experience.*

**Paw:** *I feel dizzy often. I don't have an appetite. I stand up and need to rest. I don't like traveling in the car; I feel sick.*

**MD:** *I'm sorry to hear how uncomfortable that's making you. It sounds like every day this dizziness makes it harder for you to do things.*

**Paw:** *Yes, is there a medicine to help?*

**MD:** *Medicine is one option that might help. But first I want to test your blood. Testing your blood will help us better understand this dizziness.*

**Paw:** *Are you able to help?*

**MD:** *The blood test will help me know what treatment to offer. But I think your stress and worries could be part of the problem as well. Talk to Lisa, your psychotherapist, about this, and she can help.*

**Paw:** *Ok.*

**MD:** *I'll ask my nurse to call you with these results. We'll call you within two days.*

**Paw:** *What should I do?*

**MD:** *Go to the lab right now. It's down the hall here on the right. I'll tell them you're coming and what kind of test to do. They'll take a sample of your blood. I will share this plan with Lisa and write notes in your health record so we remember and we all understand what we're trying to do.*

**Paw:** *Thank you, doctor.*

**MD:** *I hope you feel better soon.*

*[Paw decides she doesn't want to go to the lab and also doesn't want to be late to meet her daughter as she comes home from school, so she leaves without going to the lab.]*

## Introduction

Treatment planning with refugee patients can be deceptively complex. In the modern classic *The Spirit Catches You and You Fall Down*, Anne Fadiman (1998) documents dilemmas in developing a workable treatment plan for a young Hmong girl diagnosed by Western doctors with epilepsy. Her family understood her condition as *qaug dab peg* (translated from Hmong to "the spirit catches you and you fall down"). With little cross-cultural communication driving the treatment plan, the Hmong family and the Western medical staff came to vastly different conclusions about the problem, leading to vastly different ideas about the subsequent treatment plan. The consequences were dire, and the book is a highly instructive case example of an all-too-familiar collision between Western medical culture and a refugee family's culture.

While integrated care settings are designed to provide more holistic care for complex conditions, implementing refugee-friendly plans requires additional skill sets. In the treatment planning process, providers often need to offer much more explanation about problems, symptoms and recommended follow up tests; actively probe for barriers and misunderstandings; communicate frequently with other providers; empower the patient to be actively involved; and participate in ongoing re-assessment and plan revision. The benefits of coordinated care for refugee populations can include improved rates of attendance at appointments, clear understanding of multistep procedures, better health outcomes, and long-term cost savings.

This chapter highlights several strategies that enhance this process and improve health care outcomes. The chapter is divided into three parts: 1) education about problems and symptoms, 2) creation of a treatment plan with patient partnership and 3) ongoing collaboration between providers.





## PART 1: EDUCATION ABOUT PROBLEMS AND SYMPTOMS

*It is not uncommon at CVT for a client to shrug and say “I don’t know” when asked about their goals for healing. Refugee patients may not have ever been asked this question. Patients may have learned to defer to providers for medical recommendations. In the midst of war, patients may not have been in a position to imagine a future where dreams can be realized, or they may have learned to adopt a passive or helpless stance to survive massive disasters outside their control. Patients will often look to providers for direction in their treatment plan. It can be alluring to step right in and make decisions on behalf of patients. At times, this can be appropriate, when many indications of openness to providers’ suggestions and expertise are invited. On other occasions, providers who act decisively in these interactions can disempower and disengage patient participation in treatment planning.*

*So, before providers jump into a treatment plan, it is important that patients see that their own understanding is valued and that they have choices. The following examples demonstrate areas in which patient education and understanding may be an important prerequisite to creating a treatment plan.*

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### Description of the Problem

Many medical terms do not directly translate into other languages. Often a description of the problem or diagnosis is necessary to help the patient clearly understand what you are sharing. If this explicit description is not offered, interpreters may feel compelled to describe terms and may do so incorrectly. Alternatively, refugees are left to guess about the impact of their problem or will rely on family or friends’ knowledge about the condition, which also may be misinformed or incorrect.



### RECOMMENDATIONS

Offering accurate cross-lingual explanations makes it much more likely that you will engage patients in their treatment. Making use of patients’ own idioms of distress, metaphors or terminology can be of great benefit. For example, developing a shared understanding of idioms can be useful in ongoing treatment planning. The use of the patient’s own descriptions of the problem can help the patient to “buy in” to the plan and commit to treatment.

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### EXAMPLE

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When a psychotherapist met with a Karen woman, they discussed her mental health concerns extensively. Over time, the therapist recognized confusion and a denial of symptoms that appeared inconsistent with other experiences the woman described. Eventually, the psychotherapist, who had been using the term anxiety frequently, asked the interpreter to explain how the term was being interpreted for the patient. When the interpreter explained that anxiety, as he understood it, was when people feel no energy, tired and depleted, the psychotherapist recognized the need to find common ways of communicating about her problems and experiences. The psychotherapist opted to describe symptoms more directly rather than using a term that was misunderstood and not able to be directly translated into the Karen language. The Karen woman shared relief after discovering this misunderstanding, and a clearer picture of her experiences helped create a clearer picture of effective treatment options.

## Lab Results

Lab results can be confusing and overwhelming when not described in understandable terms. When this occurs, patients may feel angry that they are not informed, confused about why the lab or test was done, and worried that something terrible might be happening. While each lab result or test warrants its own unique description, severe misunderstandings of blood sugar tests, particularly the A1C, are frequent. Ongoing education and culturally specific dietary recommendations need to accompany these results so that patients can understand the meaning of this result on their day-to-day living.

Moreover, PTSD and other mental health concerns may interfere with successful treatment plan implementation. For example, injections and blood draw procedures prompt patients to either actively avoid them or bear with the procedure while experiencing overwhelming pain or fear related to their mental health diagnoses and lack of cultural understanding about what is happening and why.



### RECOMMENDATIONS

Offer clear explanation of lab results in lay terms before, during, and after the lab test. Explain how each lab draw or test is related to identifying a problem, identifying a treatment or tracking treatment progress. Ask gently about patient experiences during injections and blood draws to provide choices (e.g., looking away, talking to the interpreter) and identify coping skills that could make follow-through possible and manageable.

## Imaging Procedures

Imaging procedures are difficult to explain cross-culturally; avoid shorthand references in order to minimize confusion. Some languages use just one term for each of these procedures (MRI, CAT scan, etc.) and interpreters who are left to describe the specifics of this procedure might leave the patient confused and possibly fearful. Patients can experience panic attacks, fears of electrocution and fears of exposure to potentially lethal radiation when sensitivity to these image procedures is not addressed.



### RECOMMENDATIONS

Offer a description of an imaging procedure in layman's terms (what the machine looks like, what it will feel like, noises they might hear) and explain about how it is related to identifying a problem, identifying a treatment or tracking treatment progress.

## Acute Versus Chronic Conditions

For some refugees, chronic conditions are considered deadly or untreatable. Given the short-term nature of many medical appointments, quick explanations of the problem(s) identified by a health care professional will not always be understood by the refugee patient.

### RECOMMENDATIONS

Communicate distinctions about prognosis, such as the problem being either an acute or a chronic condition, to orient the patient to the type of treatment plan follow-through needed to successfully treat the condition. Explanations that clarify possible misconceptions here are very beneficial.

#### EXAMPLE

A Southeast Asian refugee patient with diabetes understood this diagnosis as an acute illness that inevitably, and imminently, leads to death. When management strategies described to him emphasized not eating rice, he understood the problem as one that would involve either starvation or no reasonable treatment option. He inquired about surgery, transplant options or medicines that could cure the problem. Health care providers responded to these inquiries with repudiation, which did not help him make progress in managing this condition. Ultimately, in meeting with a trusted interpreter and a new primary care physician, he learned more about the chronic nature of diabetes and was offered opportunities to learn about new cooking strategies, alternative foods, meal scheduling and medicine scheduling options. Correspondingly, he developed an optimistic vision of his future and successfully participated in his treatment plan.

## Severity

For many refugees, especially those unfamiliar with English medical terms and diagnoses, the severity of their medical problems can feel mysterious. Fear can magnify dread and hopelessness related to diagnoses.

### RECOMMENDATIONS

Be certain to offer a description of the severity of the diagnoses or problem, and identify the impact that treatments can offer when followed.

#### EXAMPLE

For a middle-aged refugee man, chronic fatigue, stomach pain, rectal bleeding and an upcoming colonoscopy had him fearing the worst. Major depression and PTSD contributed to pessimism he felt after surviving torture experiences and other traumatic war experiences. He was told to have a colonoscopy in the past, but he was not able to follow the complex instructions for timing eating, drinking and ingesting bowel cleansing preparations. This left him feeling confused, sick, scared and dreading the next procedure. He talked to his family about his impending death. He believed he had weeks, maybe months, to live. With support from a home health nurse, social worker and psychotherapist, he was able to steel himself and successfully prepare for the procedure. During this procedure, two benign polyps were removed. Afterward, he discovered that his stomach pain subsided, his rectal bleeding ceased, and he could eat without pain and discomfort. As a result, he was also sleeping better and felt more energy. He shared with his health care providers his overwhelming joy in recovering the health that allowed him to care well for his children again. Without adequate explanations of the severity of his concerns throughout this relatively routine process, his imagination and natural fear response were all he had.

## Holistic Care

Refugees may present with a number of seemingly separate health problems. Health care providers offer great benefit to their patients by addressing the impact of physical and mental health concerns holistically and, ideally, across time. An integrative, holistic explanation of various presenting complaints might be novel to some refugee patients. Patients often feel more understood and express relief and hope when they hear their providers describe how war trauma, torture, bereavement and acculturation stress impact health.

## RECOMMENDATIONS

Acknowledge the impact physical health symptoms have on emotions, thoughts and behaviors to help normalize mental health symptoms and understanding of treatment plans that address these concerns more broadly. Ask patients for their perception of their symptoms and how they interact together to help patients feel more empowered to actively participate in their treatment and understand the relationship between their physical and mental symptoms. Address potential stigma about mental health treatment by describing treatments as a way of improving health rather than only being considered in the light of “treating an illness.”

### EXAMPLE

Explanations that acknowledge what happens to the body and mind when experiencing stress or pain can be validating and educational. For example, a provider might say, “Pain, worry, anger and fear all have significant impacts on our thoughts, feelings and bodies. When we feel fear, for example, many changes occur: our muscles tense, we pay attention to what might cause us danger, our blood pressure increases, we struggle to sleep, we lose our appetite, we are quick to anger, and more.” Detailing the mind and body components to distress and disease can enhance orientation to holistic ways of treating these concerns.

## Explanation and Permission Seeking

Pain and memories of torture can be triggered during a medical exam, especially when norms for Western medical practice are unknown. Feelings of helplessness, disempowerment, fright and trauma can be triggered if care is not taken during these interactions.



## RECOMMENDATIONS

Explain thoroughly what exams you would like to do and ask permission to touch a patient’s body. Keeping in mind Dr. Ide’s description of working with torture survivors (Chapter 3), give explicit, step-by-step descriptions as you manipulate or interact with a patient’s body in any way.





## Treatment Options

Many refugee patients are unfamiliar with treatment options or choices that might be considered commonplace in Western society. Additionally, patients who are overwhelmed by multiple problems may be unlikely to explore and weigh different treatments. When patients are not explicitly encouraged to consider the pros and cons of treatment options, they are much more likely to experience the provider's recommendation as non-negotiable and reduce their engagement in treatment. Refugee patients often bring questions or concerns to their mental health providers indicating profound lack of information related to invasive procedures, painful procedures, administrative requirements of birth control options, and possible mood and sleep repercussions of medicines. These patients have expressed strong feelings of disempowerment related to their treatment plans.



### RECOMMENDATIONS

Describe treatment options, highlight costs and benefits of each option, and describe how treatments can be combined with other ongoing treatments. Make sure to explain clearly where a patient has a choice, and encourage choice as a normal aspect of participating in health care.

## Informed Consent

When refugee patients are unfamiliar with their diagnoses or available treatment options, they cannot offer fully informed consent for a particular treatment.



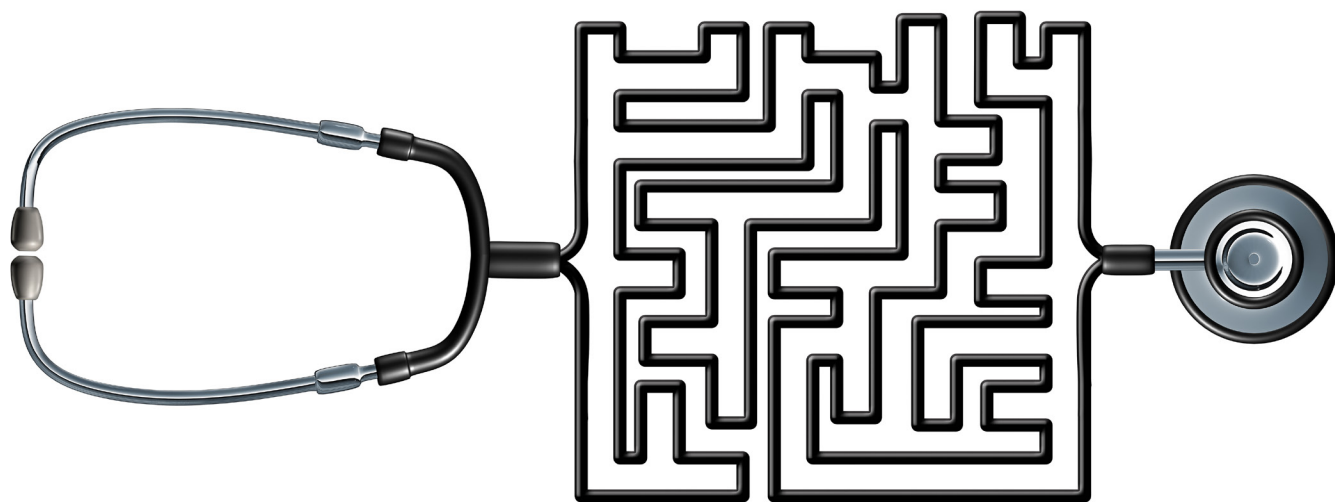
### RECOMMENDATIONS

It is imperative that health care providers working with refugee patients work hard to offer explanations of specific procedures that are clear enough for refugee patients to give consent for these services. Think of informed consent as a process, rather than a piece of paper that is signed once and then finished. Routinely check with patients on their understanding of what treatment entails and their ongoing willingness to proceed. Weave questions about understanding and interest into ongoing communication with refugee patients to promote treatment plan co-ownership.



## Provider Role Clarification

Lack of clarity about provider roles also creates frequent confusion that needs to be explained and revisited for refugee patients to understand essential elements of their care. Patients unfamiliar with roles like social worker or psychotherapist or health care navigator may need to experience the kind of help the provider offers first-hand over time to better understand the role; a one-time explanation likely will not suffice.



## RECOMMENDATIONS

Work to understand and make explicit role expectations your patient has for you and that you have for your patient. In a team-based approach, describe each of the team members and their roles in contributing to the treatment plan. Initially, invitations for refugee patients to share health concerns with multiple professionals can be helpful, especially when each professional can indicate their role in helping with the problem and refer to another professional who might most comprehensively address the specific concern. Transparency about these roles and collaboration between these team members helps to create a stable, reliable sense of help that contributes to refugee patients reestablishing trust in their relationships.

### EXAMPLE

A patient came to a doctor's office worried about a medical bill. The physician first offered empathy for the worry and took a look at paperwork that the patient has brought along. Then the physician said, "I see this is a bill. Your social worker is the best one to help you with this. Let's make sure you're seeing her soon. I'll send her a message that you brought a bill today so she knows to ask you about it." Additionally, the physician referred the client to the individual psychotherapist to manage worry and reinforced ongoing meetings with the social worker to prioritize basic needs (discussed further in Chapter 5).

## PART 2: CREATION OF A TREATMENT PLAN WITH PATIENT PARTNERSHIP

### *Explain Patients' Role in Treatment Plans*

For patients suffering from trauma, depression and losses, a passive relationship to treatment planning can be the default. Additionally, some refugees' deference to people in powerful positions, such as medical providers, can contribute to a sense that treatment will be "done to me." Western medicine often assumes a more active stance from the patient, and providers need to make this explicit. Communication in this area will help reveal motivational, educational or worldview differences.



### RECOMMENDATIONS

Inform patients at the beginning of treatment that you work together as a team (patient, provider, interpreter if present, etc.) and that their ideas about treatment will be very important. Model this with patients by asking in an ongoing way about their thoughts and offering choice where possible.

#### EXAMPLE

One way to elicit treatment plan engagement occurs when follow-up appointments are scheduled. At many busy clinics, it can be common to simply mention the next available appointment time while asking the patient to quickly respond, "yes" or "no." For disempowered patients, many will simply acquiesce to this request, believing their care is at the whim of the provider. Help a patient schedule their appointments in a manner that recognizes possible conflicts they may have with work, family responsibilities or other important appointments. While this approach can appear subtle, the impact can be great in engaging patients in their care.



## Negotiate Treatment Goals

The negotiation of treatment goals is an important way to include the patient's perspective from the beginning of treatment. Knowing the acculturation level of refugee patients can help health care providers understand the degree to which cultural norms might factor into treatment planning. Providers might find that negotiation involves expanding traditional expectations of their roles in order to be responsive and effective with refugee patients. For refugee patients, negotiation might involve considering new approaches to health.



### RECOMMENDATIONS

Use tools like the Cultural Formulation Interview (American Psychiatric Association), Kleinman's (1988) questions (see Chapter 3) or your own structural questions created once you're familiar with cultural idioms of distress. SMART goals (Specific, Measurable, Achievable, Relevant, Timely; Doran, 1981) offer a helpful structure. Communicate these goals across the provider team and with the patient; mechanisms for sharing goals within treatment teams should be prioritized.

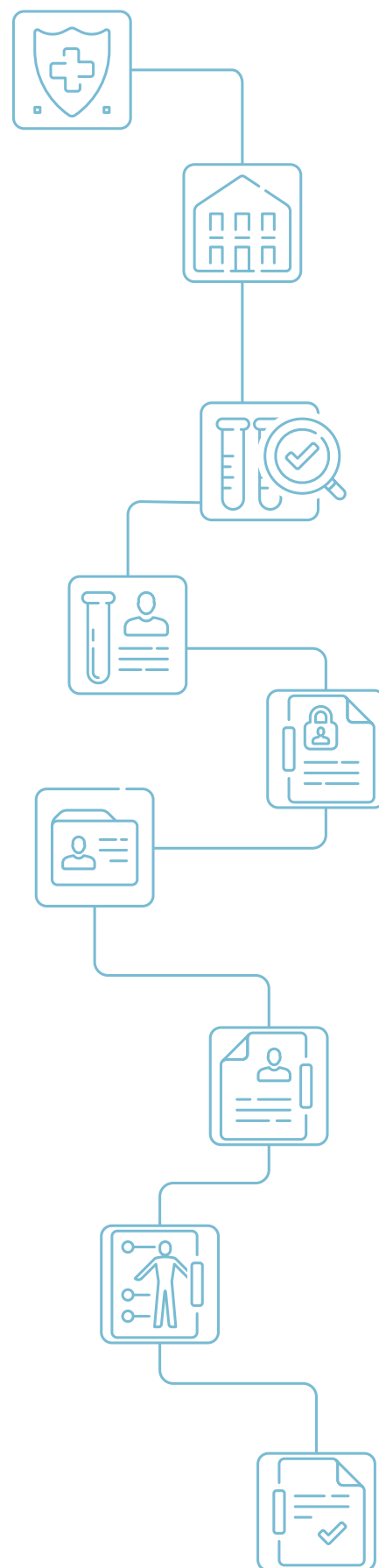
## Make Sure Patients Understand Major/Invasive Procedures

Patients are often confused or overwhelmed when the treatment plan includes a major or invasive procedure. Examples of these situations have included eye surgeries, colonoscopies, birth control implants and blood draws. Many patients may think that an exploratory or diagnostic procedure was the treatment itself.



### RECOMMENDATIONS

Explain the role of the procedure in the overall treatment plan, particularly when the procedure is exploratory. For complicated preparations (e.g., surgeries, colonoscopies, etc.), prepare a schedule that can be understood on the patient's terms and show explanatory videos of each step of the process. Work together with other providers who are involved to help prepare patients for procedures. For example, it can be helpful to have the psychotherapist work closely with the patient in situations where fear and memory problems can interfere with the success of a procedure. Working closely with a home health nurse or personal care attendant might also be extremely helpful. Knowing the care team, deciding on roles and collaborating on a plan can foster success, especially when the patient is informed and aware of what is happening each step of the way.





## Incorporate Self-Care Strategies in the Treatment Plan

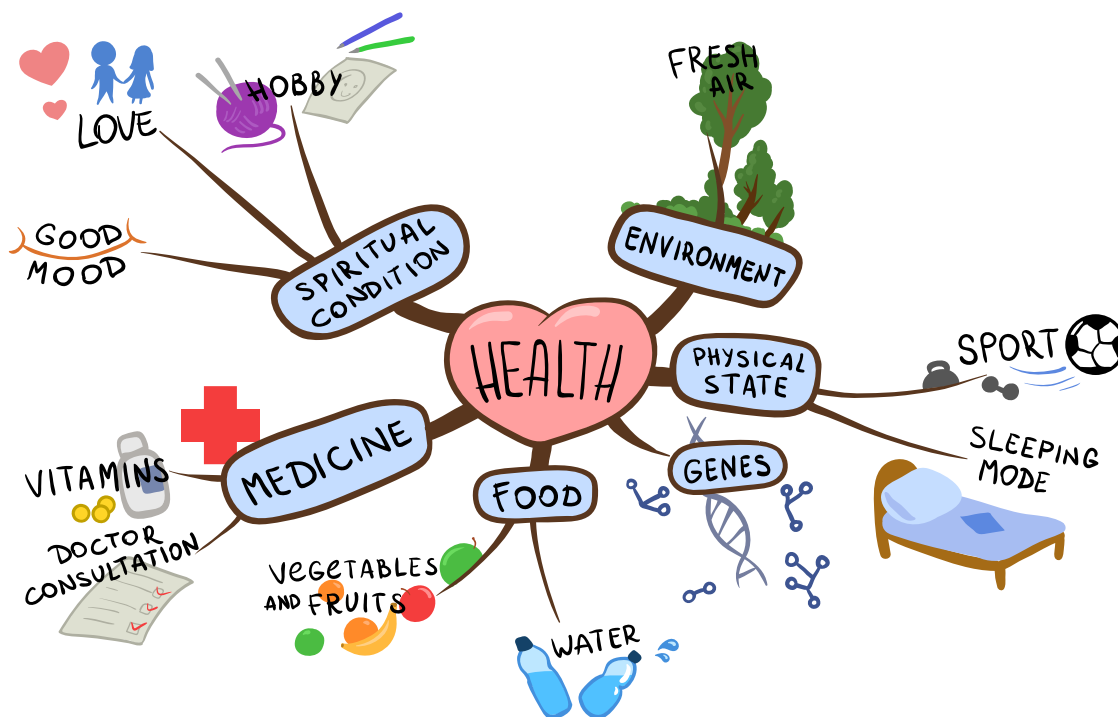
Eating, sleeping and exercise are cornerstones of good health are readily considered in health care settings. Spiritual beliefs, relationships, access to basic needs and various other activities contribute to one's basic health as well. Including these strategies involves patients more thoroughly in their care plan.



### RECOMMENDATIONS

Coordinated care means all providers can inquire about cornerstones to good health. Talking with your patient about their participation or beliefs about each of these areas contributes to a solid treatment plan. Don't ignore or minimize your influence in promoting these basic health behaviors. We encourage providers to look for opportunities to promote activities such as the following:

- Connecting with friends and family.
- Incorporating a patient's spiritual or religious practices into their treatment plan.
- Walking or including other physical activity into their daily life.
- Getting quality sleep (and offering associated education and strategies for doing so).
- Finding ways to experience joy or joyful moments.
- Listening to or playing music.
- Caring for others.
- Preparing and eating healthful food.
- Bathing oneself.
- Making art.
- Drinking sufficient water.



## Use Tools to Aid Memory and Treatment Adherence

For patients suffering from a trauma disorder or MDD, memory and fatigue are likely to be significant issues that interfere with successful adherence to treatment plans, medication regimens and health behaviors. Accordingly, treatment plans should specify supportive or compensatory behavioral interventions. It is also important for providers to understand ways that families work to compensate for such difficulties, often by assuming roles that patients once fulfilled.



### RECOMMENDATIONS

Develop tools and devices that you can have at the ready to help address patient memory, such as the following:

- Calendars.
- Journals for patients to monitor sleep, diet, exercise and/or pain.
- Reminder cards in patient's native language and appointment organization system.
- Written instructions in patient's native language.
- Images.
- Use of alarms.
- Smartphone augmentation of treatment plan (calendar apps, reminder apps, mindfulness apps, language learning apps, soothing music apps, guided imagery apps, voice recording apps).
- Utilization of supportive family members or PCAs in the home.
- Reminder calls for appointments.



## PART 3: ONGOING COLLABORATION BETWEEN PROVIDERS

### *Determine the Logistics of Coordinated Care*

Providers need to review ways in which collaborative care coordination can effectively take place. Will you use your medical record? Communicate via a messaging system? Share notes? Use phone calls? Consult in-person? Who will initiate referrals? Which individual or department will be responsible for follow through? These are among the most important questions to address when constructing a collaborative care model that will benefit coherent treatment plan construction with refugee patients.

### RECOMMENDATIONS

- Describe explicitly how coordinated care works when meeting with your refugee patient. Mental health providers, for example, need to be clear about what information their patient is comfortable sharing across professional boundaries, and professional ethics and laws need to be abided by when making these considerations.
- In integrated care settings, name one member of the patient's provider team as the point person for the patient's treatment plan until a patient is able to fully take on this role themselves. This point person can address foreseeable problems in successful implementation and can maintain the thread of clinical hypothesis testing that can otherwise be lost.

#### EXAMPLE

A preliterate patient from West Africa informed her social worker that she had many health concerns but did not know how to tell her doctor in the short amount of time in their appointments. She said that she had some medications but they looked different from the medications she was given in West Africa so she did not want to take them. The social worker worked with the patient to schedule a longer appointment with her doctor. The social worker spent time with the patient, making a list of her worries and questions on a piece of paper. The social worker provided a copy to the patient and faxed a copy to the patient's clinic. At the next appointment, the doctor looked at the list of questions, took the time to ask more about each concern, and set the patient up with a clinic care coordinator to follow up with the patient at each visit to ensure understanding of the treatment plan. The patient later told her social worker that she felt much better about her health and felt her clinic cared about her and her wellbeing.

### *Create Shared Treatment Plan Across Multiple Providers*

Often, coordination time is not built into schedules or reimbursed. Billing challenges serve as an obstacle to effective care for refugees; but insurance changes may be on the horizon that will reward coordination of care, better management of chronic conditions, and consultation between mental health and physical health providers. In Minnesota, billing for psychotherapist consultation with the primary care provider can be successful, and providers in other areas may use or advocate for similar billing options.

## RECOMMENDATIONS

Use a model or a tool to develop a treatment plan across disciplines.<sup>3</sup> We suggest using a collaboration tool such as the one offered in the example below. Both physical and mental health professionals can contribute to this tool with patient consent. For providers, such a tool can be implemented at either a regular interval or when needed prior to interventions from another discipline. It can be used either as a document to be shared or as an agenda for collaborative meetings. We have found that this style of collaboration also fosters a patient stance that focuses on solutions and options, as opposed to feeling helpless. For providers as well, it can help ameliorate a sense of isolation or total individual responsibility for a patient's care.

### EXAMPLE

#### Interdisciplinary Collaboration Tool

##### *Active Diagnosis List*

##### *Active Medication List*

Does patient have access to all medications?

Any discrepancy between patient's regimen understanding and physician's prescription?

##### *Current patient concern(s)*

Intersecting household members/children's health concerns

##### *Resources patient has to address the concerns*

Internal:

External:

##### *Current goals*

Note any discrepancies between provider/patient

Steps needed to achieve goals (Referrals pending; behavioral steps; appointment schedule and frequency)

Short-term treatment plan

Long-term treatment plan (recognize trauma/torture, ACEs and SDH as appropriate)

Barriers to treatment plan adherence

##### *Progress Made*

##### *Other providers actively providing care*

##### *Current focus of collaboration*

##### *Plans for next step(s) in collaboration*

<sup>3</sup> The many models and levels of coordinated care cannot be presented here but these SAMHSA websites could serve as useful starting points:  
[https://www.integration.samhsa.gov/about-us/esolutions-newsletter/esolutions\\_september\\_2015](https://www.integration.samhsa.gov/about-us/esolutions-newsletter/esolutions_september_2015)  
[https://www.integration.samhsa.gov/Integrated\\_Treatment\\_Tool\\_Case.pdf](https://www.integration.samhsa.gov/Integrated_Treatment_Tool_Case.pdf)

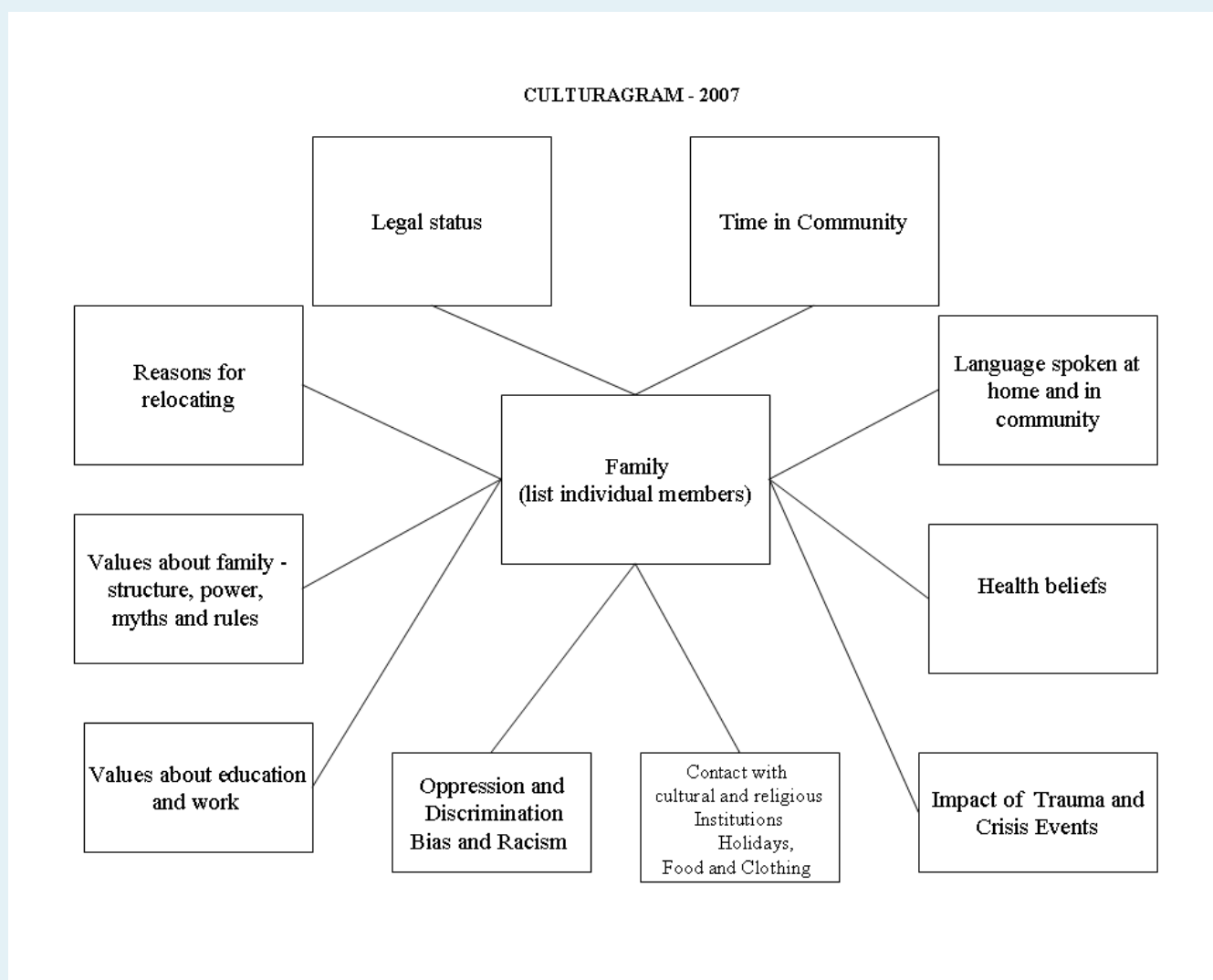


## Consult With Care Team Members

Health care providers should consider implementing various strategies to enhance collaboration in their unique setting. Note that these suggestions are in reference to collaborations reflecting shared buy-in when working in co-located or integrated care settings (versus simple referral to an outside provider).

### RECOMMENDATIONS

- Communicate via the electronic medical record, highlighting both patients' strengths and presenting problems.
- Consider use of a culturagram or ecomap or other means of graphically displaying important aspects of a patient's life and treatment plan (see inset below).



Graphic: Reprinted from "Visual assessment tools: The culturagram—Interview with Dr. Elaine Congress," by E. Congress, December 10, 2008, *The Social Worker Podcast*, retrieved from <http://socialworkpodcast.blogspot.com/2008/12/visual-assessment-tools-culturagram.html>.

- Offer brief updates of symptoms, problems, communication difficulties and strengths to providers in advance of next appointment.
- Encourage phone conversations to address more detailed concerns or strategizing of treatment plan recommendations.
- Identify an individual who will track the treatment plan when the patient is not yet able to, including monitoring intervention efforts and patient understanding.
- Keep the focus on developing the patient's capacity for tracking and managing their treatment plan implementation over time.
- Understand the role of your specialty and be open to recommendations from other specialties that might overlap with your treatment plan.
- Acknowledge inherent tension between overlapping roles when working with patients and address any conflicting recommendations.

### EXAMPLE

A refugee patient with chronic pain shared with her social worker that her doctor told her not to talk about her leg pain anymore during their appointments if her symptoms remained unchanged. In reviewing the appointment notes, the doctor reported communicating that she advised the patient to let her know if her symptoms changed and then moved on to another topic. The social worker shared the patient's understanding of the doctor's instruction in a brief consultation, and the doctor asked the patient about her pain at the next appointment and clarified her communication.

## *Expand Your Professional Frame*

The traditional, specialized role health care providers have been trained for may lead to successful treatment for mainstream patients but may contribute to inequitable treatment and outcomes for refugee patients. Lack of attunement to refugee patients' self-efficacy in multiple areas (e.g., use of Western calendars, norms for picking up medications, overlapping impact of stress across physical and mental health domains, detailed instructions in preparation for medical procedures, timing of medication administration, over-the-counter medication options, etc.) can be problematic when trying to implement successful treatment plans.





## RECOMMENDATIONS

Expanding your frame while collaborating with others in the integrated care setting will significantly help refugee patients. For example, while psychotherapists might not traditionally see it as their role to help explain how the pharmacy system works in the United States or how to use a Western calendar, offering these explanations can be essential to successful treatment plan integration. Similarly, physicians might not see it within their traditional role to develop a plan for physically picking medicine up from the pharmacy; but failure to do so might result in a treatment plan that has no chance of succeeding. In order for the treatment plan to be effective, interdisciplinary teams need to regularly move beyond our traditional professional frames to foster success.

### EXAMPLE

The calendar in Ethiopia has 13 months, so translating dates for clients can be confusing. Furthermore, many countries in the world list the day, then month, then year. Many providers in the U.S. medical system are unaware of differences between calendars, which can lead to mistakes in birthdates, gathering medical history, or scheduling future appointments. Learning about different calendar and time practices will help providers and patients develop a shared understanding of a patient's history and outlook.

## SUMMARY OF RECOMMENDATIONS

- Before launching into a treatment plan with a refugee client, first ensure they understand your assessment. Make sure patients understand the terminology you are using. Be sure to clearly explain tests like lab results and imaging procedures. Differentiate between acute and chronic problems and describe the severity of a problem. Explain the benefits and interrelatedness of treating physical and mental health symptoms. Seek permission and give options for your recommendations.
- When creating a treatment plan, encourage patient involvement. Negotiate treatment plans (page 65). Create a single shared treatment plan with all the patient's providers (page 69). Explain and seek permission for any planned invasive procedures which may be frightening to a refugee survivor. Include self-care strategies in the treatment plan. For patients with memory difficulties, use aids (page 67) to increase the likelihood of treatment plan success.
- Collaborate with team members to implement treatment plans. Inform patients the team will work together and share information; name one team member as the point person for the plan. Figure out logistics within your clinic for mechanisms to communicate regularly about patient care and the plan.

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## CASE EXAMPLE: RESOLUTION

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In this resolution, we see ways in which Dr. Green incorporates several best practices while taking responsibility for communicating well. A week after Paw's primary care appointment discussed at the beginning of this chapter, Paw goes to the hospital on an emergency basis due to increased dizziness symptoms. Paw attends a follow-up appointment with Dr. Green after her hospitalization.

**MD:** *Thanks for coming in to follow up with me today. I'm sorry to hear your symptoms did not improve and that you went to the emergency room to receive help. That sounds like a difficult experience you went through. How are you feeling today?*

**Paw:** *I am feeling the same. Sometimes better sometimes worse.*

**MD:** *Did the hospital staff give you paperwork when you left?*

**Paw:** *Yes, [hands over discharge paperwork] they asked me to have this appointment with you.*

**MD:** *[Reads paperwork]. Ok, thank you; this is very helpful information. We'll scan it into your chart here, and I'll also provide this information to your psychotherapist, Lisa, to help her address your needs. Can you explain to me more how you were feeling when you went to the hospital? It seems that I may have misunderstood some of your symptoms during our last appointment.*

**Paw:** *I feel so dizzy that I couldn't stand and couldn't eat. I feel sick when traveling in the car, but I couldn't take it anymore, so I went to the emergency room.*

**MD:** *After our last appointment it looks like you did not get your blood drawn, is that right?*

**Paw:** *Yes, I just went home.*

**MD:** *I know we talked about a plan to have your blood drawn. Were you not available or interested that day to go to the lab?*

**Paw:** *I did not want to. I do not think it will help improve my health.*

**MD:** *Thank you for sharing that with me. Could you help me understand why?*

**Paw:** *I have heard that doctors here have blood drawn when they do not know what is wrong even if it will not help. It is painful and I do not like seeing blood; it brings back memories of difficult times.*

**MD:** *That makes a lot of sense; I can see why you would choose not to have your blood drawn. Please tell me when you do not agree with my recommendations though. And in turn I will ask about your perspective and understanding of our treatment plan. That way we can continue to improve your health.*

**Paw:** *So do I have to have my blood drawn?*

**MD:** *You always have a choice. You can always decline my recommendations. But I would encourage you to have your blood drawn today. I think there is a good chance that you have an iron deficiency and low potassium. That could cause dizziness. This test will*



*help us determine if that is the cause. It will also tell us exactly how much of which supplements and medications you will need to reduce your dizziness. The only way for us to know clearly is through this blood draw. The blood draw will also help us know if there are other illnesses or deficiencies making you feel dizzy. Do you remember what happened the last time you had your blood drawn?*

**Paw:** *Yes. It was really fast — they inserted a needle into my arm and I felt a little pinch. I saw the tube fill up with blood and felt nauseous.*

**MD:** *It's common for people to feel that way. I can speak with the lab technician about guiding you through the process. There are techniques that the technician can use to make it easier. Did you feel nauseous for a long time afterwards last time?*

**Paw:** *No, it was just at that moment and passed. I was so afraid because I didn't know what was happening.*

**MD:** *If you want to go now, I will call the lab technician on duty. I will make sure she does the blood draw at a pace that is comfortable to you and that she explains what is happening as she does it. A nurse will call with results two days after today and explain what they mean. I want to schedule an appointment to see you in one week.*

**Paw:** *Thank you, Doctor. I will plan to do it now.*

## DISCUSSION QUESTIONS

*Consider your current role as a provider:*

- › How do you conduct treatment planning? How can you increase coordination?
- › How do you assess your patient's understanding of their treatment plan? What are barriers to understanding treatment planning?

*Imagine you are in Paw's position as a patient:*

- › Do you understand your treatment plan? What would help increase engagement and understanding?
- › What aspects of U.S. health care culture could you imagine as confusing or complex? What would increase your ability to navigate these systems successfully?



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# Attending to Basic Needs

## CHAPTER 5

### CASE EXAMPLE

Paw is meeting with her primary care physician for her follow-up visit regarding her headaches. Paw talks with her doctor with help from a professional Karen interpreter.

**MD:** *Hi Paw, nice to see you today. How are you doing?*

**Paw:** *I am the same; sometimes I am good, sometimes I have pain.*

**MD:** *I'm sorry to hear you are still having pain. How is the new headache medication working for you?*

**Paw:** *I think it helps sometimes.*

**MD:** *Ok, great; glad to hear it was helpful. Are you still taking it?*

**Paw:** *Not anymore. I finished the bottle a while ago.*

**MD:** *Do you know how to obtain refills?*

**Paw:** *I do. I go with my friend, but I have not been able to go because of my schedule. I have been attending many appointments for my son, and they keep doing tests but do not know what is wrong with him.*

**MD:** *I understand. Let's go ahead and request a refill for that medication and have it sent to your home. Would that be helpful?*

**Paw:** *Yes, thank you. Our apartment door does not lock so people come in and out of the building. I'm not sure I will get the medication if the package is left in the hall.*

**MD:** *I'm sorry to hear that. The pharmacy usually requires a signature so you should get it. Is 123 Main St. still your address?*

**Paw:** *No, we moved a few months ago, but I still have not been getting letters related to my health insurance or food support since we moved.*

**MD :** *I will update your address in our system here at the clinic which will go to the pharmacy. Be sure to update your address with other agencies and the post office. Anything else for today?*

**Paw:** *Ok thank you. Can I have a note that I was here today for my job? I have been missing a lot of work, and I think I will get fired.*

**MD:** *Of course; here is a note confirming you had an appointment today.*

## Introduction

As Maslow (1943) proposed in his hierarchy of needs more than 70 years ago, peoples' basic needs must be met in order for people to attend to higher order concerns. For example, one can hardly focus on what brings one greatest fulfillment in life when struggling to find the food, shelter and safety one needs to survive. In health care settings, this might be understood as acute physiological and safety needs being met and stabilized prior to orientation toward proactive efforts to achieve optimal health and well-being. It is also true that patients will often only seek medical care either when they are facing an acute problem or crises or if they can envision how medical care could improve their overall health. Therefore, refugee patients may not bring their basic needs to providers' attention without being asked, especially when these problems are chronic in nature. Refugee patients have told us they don't want to "burden" providers with their problems or that they are not sure how providers could even help. Some patients, however, do proactively and regularly voice stressors, particularly immediate ones related to basic needs. Routine assessment of a refugee patient's basic needs (e.g., safety, housing, and food) with referrals as needed helps patients receive stabilization support when needed.

Providers can play an important role in helping patients experience stability and having their basic needs met. A full range of treatment goals is supported when a basic needs assessment informs what a path toward stabilization looks like. Assisting refugee patients in this way leads to improved physical and mental health and development of an expanded future orientation. This chapter is divided into 10 sections. The first section addresses assessment of basic needs. The remaining nine sections include specific information about common issues related to basic needs of refugee patients, including safety, determinants of health, domestic violence, health insurance, income, family needs, legal status, housing and transportation.

## Assessment of Basic Needs

There are many reasons refugee patients may have unmet basic needs, such as language barriers that inhibit their ability to advocate for themselves. Examples of such challenges include speaking with a landlord about a safety concern with their housing or comprehending an English language letter received in the mail that describes steps needed to reinstate health insurance or obtain food support benefits. Approximately 60% of asylum seeker and refugee clients receiving care at CVT's St. Paul Healing Center report difficulty understanding or communicating in English. These language barriers present substantial challenges to accessing and engaging with health services. Moreover, over 80% of clients state they have unmet basic needs when beginning care at the St. Paul Healing Center. Newly arrived refugees, and refugees with physical or mental health symptoms that prevent them from work, usually have limited or no income. Nearly all of our patients qualified for food support assistance, meaning they live at or below 165% of federal poverty guidelines. People in poverty experience constant stress to make ends meet, and many are unfamiliar with the profound impact of this stress (Mathewson, 2017).





In addition, refugees are simultaneously coping with the impact of war trauma, torture and the cultural adjustment of relocation in a new country. For example, when stress and fear are overwhelming our brain focuses energy and attention to basic safety, such as the fight and flight response. When this system is engaged, our connection to our prefrontal cortex, which is responsible for executive functioning (such as planning ahead, having a good working memory and exercising self-control), is disengaged. This disengagement impedes the ability to feel in control of one's life and engage in a treatment plan. For refugees, this stress is compounded by previous and sometimes ongoing trauma.

Countless patients express feeling worried and losing sleep over letters they received in the mail in English. They wonder if the letter is an advertisement, a bill, or a legal notice requiring an immediate response. They are not sure who they can trust to accurately read the mail and advise them on what action is needed. Patients with these needs have stopped mental health services when providers have told them they cannot help with these daily stressors and did not provide an appropriate referral.

## RECOMMENDATIONS

Assess the basic needs of your patient to understand how patients interact with their environment and health. Helping a patient get their basic needs met can be time consuming and frustrating. Reading mail and helping a patient acculturate to life in the United States within their circumstances may be outside your normal scope of practice. If attending to basic needs is outside your role, it is important to become familiar with referral options you can make to support your patients—for example, to a social worker, financial worker or community based organization. It is important to follow up with these referrals after they have been made to ensure services began, given the numerous breakdowns that can occur during the referral process (see Chapter 4 on treatment planning for more information). Unmet basic needs are key elements that often go unaddressed, resulting in daily instability. Continue to assess basic needs with your patient until stabilization is reported.

Some clinical tools have also been constructed to help assess such needs. CVT developed the Social Circumstances and Functioning Inventory (SCFI) to assess safety, stability, education, employment, adjustment to new cultural environment and community engagement. The 37-item instrument has been normed on data collected with torture survivors receiving direct services at CVT, and has demonstrated strong reliability and construct validity (Vukovich & Tracey, 2017). CVT hopes to have this tool available in the near future.

### EXAMPLE

Teaming up social work support and psychotherapy has been extremely helpful in the situations just described. Often, both the fear and anxiety associated with these experiences as well as the practical steps to address the concerns need to be addressed. Psychotherapists may be most helpful in this situation by acknowledging the overwhelm and fear elicited by such a situation, and by teaching skills in how to manage one's arousal state and act most effectively.<sup>4</sup> This intervention needs to be accompanied by practical support to address the problems; a social worker can either provide that support directly, or help the patient identify resources (whether internal or external) to do so.

<sup>4</sup> See, for instance, Siegel's (as cited in Good Therapy, 2016) concept of the "window of tolerance," which describes the zone of experience in which a person can act most effectively.

# SAFETY

## *Suicidality*

Assessing for risk is a critical element of working in primary care settings. Each clinic and specialty has its own protocols (and often specific screeners) to assist with risk assessment. It is vital to ensure that risk assessment procedures are culturally relevant to a given refugee group. For example, in working with Karen refugees, it is important to understand that present and future tenses are understood differently than in English. When asked if they have thoughts of hurting themselves or others, Karen patients might respond “no,” when in fact they had such thoughts earlier in the day but were not having them at the time the question was asked. Alternatively, some Karen patients might answer affirmatively to a question about suicidal thoughts and, upon further assessment, reveal they had those thoughts years ago. A provider missing this detail may inadvertently miss an imminent suicide risk or send a patient to the hospital with no active ideation. More information regarding language considerations and working with interpreters is discussed in detail in Chapter 7.



## RECOMMENDATIONS

Validate and normalize the experience of thinking about death and contemplating suicide or homicide while also asking about these experiences directly. For example, you could say, “We know sometimes people have thoughts of wishing they were dead or had thoughts of harming themselves or others. Have you had these thoughts?” Follow up with questions about past, present or recent nature of such experiences, and ask additional questions about thoughts, intent, plan or means related to either suicide or homicide. Be sure to carefully assess for tense; assess if the suicidal thoughts are happening now or if they happened in the past. This may not be evident in an initial translation.

Work in partnership with primary care staff and security when hospitalizations are required, however rare. Sensitivity when addressing risk and hospitalization is needed. For example, ambulances and uniformed officers, including police, can be triggering for survivors of torture and war trauma. Whenever feasible, ask emergency personnel to enter the building from a less public setting, such as a back door, to reduce triggering PTSD symptoms of others. Patients need to be informed of what is happening, what to expect and why they are being hospitalized to support safety and well-being.

Additionally, consider steps to help the patient notify their family or close friends as to their whereabouts when being hospitalized. Due to limited phone access and limited understanding of U.S. health care procedures, family members and patients are at risk for being out of contact for extended periods of time, with family not knowing what has happened to their loved one.

For some clients who are desperate, suicidal ideation may seem like the only available solution to their problems. Refugee patients commonly express suicidal ideation when feeling unable to manage their or their family's basic needs, including maintaining housing, food, or health insurance. Supporting these basic needs either directly or through referrals quickly helps in stabilizing suicidal ideation.

## Homicidality

Homicidal ideation is sometimes reported as a solution to feeling powerless or worthless. But homicidal risk is quite rare and is often used as a general expression of frustration. That being said, it is important to assess homicidal ideation carefully.



### RECOMMENDATIONS

Use questioning to elicit more information. Ask directly about homicidal intent—for example, “I hear just how angry you are that this happened. You mentioned wishing this person was dead. Do you have any thoughts of hurting him?” If any intent is noted, ask directly about intent and means. If a threat exists, follow Duty to Warn reporting requirements and seek consultation as needed.



## Child Abuse/Neglect

Child protection concerns also occur when patients are overwhelmed with stress. Patients benefit from collaborative problem solving with providers to address these needs before a crisis emerges.



### RECOMMENDATIONS

Clinicians need to report child neglect and abuse in accordance with mandatory reporting requirements even if it is clear that incidents of abuse or neglect occurred due to unmanageable stress. There are significant benefits in reminding patients why a report was required and offering encouragement that potential child protection involvement could help put supports in place to address the overwhelming stress in the home. Whenever feasible, make the report with the patient present to promote transparency.

### EXAMPLE

A Karen woman reported abusive actions by her husband in front of their children that could also be perceived as neglect given her inaction in this situation. Relationship dynamics with her husband and lack of awareness of U.S. child protection laws left this patient without any idea about what options she had to address the problem. Her providers offered her information about their role as mandated reporters; however, they also described how interaction with these offices could be used to her and her family's advantage. With transparency and guidance throughout this process, the woman was able to see the providers' role as advocates for her and her family's health. She engaged with child protection services, and she was able to establish boundaries in her relationship with her husband that led to interventions resulting in awareness and adherence to U.S. laws, education about parenting strategies and alternatives to violence, and improvements in communication and the relationship she had with her husband.

## SOCIAL DETERMINANTS OF HEALTH

As a health care provider, you are likely familiar with the social determinants of health as conditions that influence patient health outcomes.

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education			
Support	Walkability				
<b>Health Outcomes</b> Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations					

Graphic: Artiga, S. & Honton, E., *Beyond health care: The role of social determinants in promoting health and health equity*, by (2018, May 10). (The Henry J. Kaiser Family Foundation, [2018, May 10]). Retrieved from: <https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity>, February 14, 2019.



Despite increasing knowledge of the impact of these social determinants on health, primary care clinics often do not have the capacity to support patients in these areas. But health inequities continue to grow when these social determinants go unaddressed. Providers in primary care clinics should feel emboldened to support patients when faced with nonmedical challenges that impact their health, such as unemployment or experiences of discrimination. Health care providers should learn about appropriate referrals to social services that can support patient stabilization in areas outside their scope of practice, and where there are gaps, advocate for more appropriate social services within or outside the clinic setting to support patient health.



### RECOMMENDATIONS

Be aware of your patient's ability to accomplish your recommended actions in light of the social determinants of health. Take, for example, the case study above when Dr. Green encourages Paw to update her address with the post office and county office. It is unclear if Paw is able to follow through on this action given barriers addressed in the social determinants of health (including support, transportation, literacy and language). Maybe she can independently complete this task and the recommendation from her provider is all she needed. More often than not, however, more education or other support is needed for seemingly routine tasks such as updating an address, which has significant consequences including lapsing insurance, losing food support and missing bills. See the case resolution summary at the end of the chapter for more guidance on resolving these issues.



## Domestic Violence

Women and children are at particularly high risk for experiencing domestic violence when social structures are disrupted by torture, persecution, or armed conflict (United Nations High Commissioner for Refugees, 2003). Many refugees experience rape during or while fleeing conflict, and sometimes it is perpetrated by a domestic partner. Once resettled in the United States, as traumatic experiences and stress continue, domestic violence may continue or begin. Approximately 14% of asylum seeker and refugee clients at CVT report they have experienced domestic violence when beginning treatment. Many more clients share experiences of domestic abuse or family violence as treatment progresses and they have established safety and rapport with CVT providers. Some perpetrators turn to violence when experiencing frustration and identity loss during temporary and permanent resettlement. Refugees often experience isolation, a domestic violence risk factor, due to unemployment, lack of English skills and limited finances (Rees & Peese, 2007). Along with other safety concerns, ongoing domestic violence is a major barrier to improvement in treatment goals.

Providers in primary care are often the first to ask refugee patients about safety in the home. While a useful first step, there are many reasons a refugee patient would decline to acknowledge safety concerns even if domestic violence is occurring in the home. Reasons for this nondisclosure include fear, concern about child protection involvement, social isolation, aggressive behaviors not identified as domestic violence (for example marital rape or physical intimidation), emotional or verbal abuse not considered domestic violence, love of partner, economic dependence, cultural considerations of partnership or marriage, and lack of hope for improvement even with disclosure. In addition, varying levels of domestic violence may be normed as permissible in a patient's country of origin.



## RECOMMENDATIONS

Build trust to increase the likelihood of patient disclosure of domestic violence. Openly acknowledge that domestic violence takes place—for example, “Sometimes people experience violence or are scared that violence could take place in their homes. Do you have this experience or feeling?” Explain potential improvement with treatment to help patients feel more comfortable with disclosure. Providers need to ensure that patients are aware of mandatory reporting requirements and explain the importance of safety for children when violence is present in the home. Patients should be able to receive support without disclosing that they are experiencing domestic violence. Resources need to be made available in the exam room or waiting area for patients to access, such as pamphlets in a patient's language that offer domestic violence resources.

When domestic violence is present, providers need to obtain more information to understand risk. It is important for providers to understand if weapons are involved or accessible. Providers need to be familiar with the cycles of violence to assist patients with identifying and understanding common domestic violence dynamics. The three phases, according to the Domestic Abuse Project (n.d.), are as follows:

**Phase 1: Tension Building.** *This is a period when tension mounts and small outbursts occur. Victims often feel like they must be very careful so that their abusive partner will not explode. Some describe this time as “walking on eggshells.”*

**Phase 2: Acute Battering Incident.** *This is when an abuser decides to become acutely abusive. Victims' behavior cannot change the outcome. They often feel helpless and depressed.*

**Phase 3: Relief Period.** *This is a period of reduced violence and relative calm also known as the “honeymoon” period. Some abusive partners may become contrite and ask for forgiveness, promising that the violence won’t happen again. Victims may want to believe their partner’s promises, or they may remain in the situation out of fear of what their partner will do if they leave. Research shows that without intervention, domestic violence increases in intensity over time. The abuse progresses to higher and higher levels of violence, rarely dropping to lower levels.*

If patients decide to pursue an order for protection from the abusive relationship, connect them with organizations to help them overcome access barriers, such as language and transportation, given the limitations for non-English speakers and potentially isolated refugees.

### EXAMPLE

One patient disclosed having past significant domestic violence in her marriage. Psychological abuse was still present and the clinicians believed the threat of violence in the home was present. The patient attempted to obtain an order for protection from her husband, but no interpreter was available. After this failed attempt the patient declined to pursue separation from her husband, citing that her husband was committed to improving their relationship.

The focus for clinicians was to increase safety in her home while she remained in this relationship. Clinicians assisted the patient to identify and communicate boundaries and plan for safety. During the course of treatment the patient reported feeling more confident, saying she believed she could “stand on her own two feet,” which she had not felt previously. Her symptoms decreased, she began working full time, and she expressed feeling more able to live independently and separate from her partner with support from a community-based women’s organization.

## Health Insurance

Refugees generally qualify for medical assistance health insurance upon arrival in the United States. This health insurance is a source of stability for refugee families, though maintaining active insurance status can be a source of stress. In Minnesota, health insurance renewal letters are sent by mail in English, and individuals are responsible for obtaining help from an English-speaking contact or social services agency to ensure the required application and proofs are sent in on time. Patients express feeling in limbo while their renewals are being processed, often canceling any medical appointments for themselves or family members to avoid the risk of high bills they cannot afford. Primary care clinics and patients both benefit when patient health insurance statuses remain active. Appointments are more likely to be kept, insurance billing is more stable and patients feel more confident to schedule follow-up appointments as recommended.



## RECOMMENDATIONS

Many clinics have recognized the need to support families in maintaining health insurance. Clinics with refugee populations have found benefit from providing assistance with insurance renewals in addition to other stabilization services given this mutual benefit. Assign and allot time to a staff member to help refugee patients not only complete the renewal paperwork but also follow up with the state or county insurer when there are delays or requests for more information.

### EXAMPLE

A refugee patient last met with her provider six months ago. She had shared feeling she was in a crisis situation and had thoughts of hurting herself from desperation due to feeling overwhelmed with basic needs unmet for her family. They had a follow-up appointment scheduled for one month following a meeting with CVT, but it was cancelled since the patient's medical assistance insurance had lapsed. This patient reported having no contact from the clinic or other providers to reschedule over the last six months. During her meeting with CVT the patient shared their situation had not improved. Despite awareness that this patient was in crisis, no indication had been included in her chart to flag a follow-up call or support.

## FINANCIAL STABILITY

### *Income*

Everyone needs access to money to pay rent, buy food and purchase basic items. Refugees generally receive three months of cash benefits for these basic needs when they arrive in the United States. At least one family member is then expected to work, often at low-paying and physically demanding jobs. Asylum seekers cannot apply for work authorization until 150 days after their asylum application is submitted. This leaves asylum seekers to rely on family, community members, faith communities and social service agencies to provide for all of their basic needs. Patients with significant physical or mental health symptoms may not be able to maintain work in this type of environment until their symptoms improve. Over 80% of asylum seeker and refugee clients at CVT report they are unemployed when beginning care. Patients feel overwhelmed that they will be unable to maintain employment and provide for their family.



## RECOMMENDATIONS

Help problem solve with patients regarding these concerns that impact their ability to prioritize their health. Providers can often help communicate concerns to an employer and assist in reassigning the patient to a role that better meets their abilities. Referrals to culturally appropriate employment services can assist patients with finding jobs that match their interests and capacities. If your patient's diagnoses reach the level of a disability, community employment agencies can help to advocate for reasonable accommodations in your patient's workplace to help maintain employment stability.

Government programs are available for patients unable to work. Familiarize yourself with resources that can support patients in applying for and maintaining state and county cash assistance programs. Providers' certification regarding a patient's inability to work is often needed in a timely manner. Acquaint yourself with forms and timelines required for government programs. When patients have long-term symptoms, providers play a key role in supporting supplemental security income (SSI or SSDI) applications. Communicate openly with patients regarding their symptoms and their short-term and long-term ability to work, in order to support their financial planning.

### EXAMPLE

A patient was informed her government cash assistance would stop immediately. After helping the patient follow up with the government agency, CVT learned her primary care provider did not complete the monthly medical opinion form confirming the patient could not work for the next 30 days. CVT consulted with the primary care provider who agreed to complete the form but did not return the form as planned. The patient presented to CVT reporting having thoughts of suicide and homicide, explaining she would rather die with her family than become homeless since they could not pay rent without the cash assistance anticipated. CVT assisted the patient to manage her stress while following up with the doctor and the government office to reinstate the patient's cash assistance to pay rent.

## Food

Over half of asylum seeker and refugee clients at CVT report they are not able to access enough food to feed their families when beginning treatment. Patients may report having access to food, but when asked for more details report having only one small meal per day.



## RECOMMENDATIONS

Ask patients directly about their access to food and food intake. There are usually food support programs available to low-income patients. Be aware of resources such as food shelves, and help patients problem-solve access barriers including transportation and limited time availability. Educate patients regarding nutrition and food in the United States, including understanding food labels for patients literate in English. CVT regularly has nutritious and shelf-stable foods on site (including almonds, granola bars, and apple sauce) in case patients are hungry, to enable focus during appointments. See Chapter 6 for more information regarding nutrition support within behavioral health.



## Family Needs

Refugees are usually settled in family units. Many refugees come from collectivist cultures where the well-being of their family (including extended family) is perceived as just as—or more—important than their own individual wellbeing. A patient in this context will be more motivated to address concerns impacting their family unit compared to their individual health. For example, a patient may want to improve their mental health as it relates to their ability to effectively parent their children. Addressing these family needs is a way for providers to build relationships with patients and understand how they are interacting with their environment. Refugee parents are tasked with navigating new and complex systems for their children, including the health, education and social systems.

Refugee patients often express confusion and distress regarding the health of their family members. Some patients might have children with illnesses they do not understand, or might think a close family member had only a few months to live when diagnosed with a chronic condition such as diabetes. These stressors impact a patient's outlook and daily functioning.

## RECOMMENDATIONS

Assess family basic needs. Providers need to help connect patients to free or low-cost resources in these areas. Refugees, in many U.S. locations, may be experiencing a cold winter for the first time. Education regarding this cold weather, conditions such as frostbite, and strategies to keep warm are critical. For school readiness, children may also need school supplies, uniforms, paperwork completed, and internet at home. Obtain releases, when appropriate, to consult a patient's family member's chart or to consult with a treating physician to help the patient and their family understand the family member's prognosis. Help patients follow up with their child's health care provider, school nurse or social worker as appropriate regarding concerns and action needed from parents to support their children's physical or mental health.

### EXAMPLE

One patient was regularly missing primary care and CVT appointments. He would confirm that he would attend the next scheduled session, but then would again miss the appointment. CVT learned after further assessment that his child was having concerns at school and last minute school meetings were being scheduled that conflicted with his appointments. The patient noticed his son was having similar symptoms to his own, including withdrawal and irritability. CVT obtained releases of information to consult with the school and assisted in coordinating a referral to mental health services for the son. After a few months, the patient's attendance at primary care and CVT appointments improved. The patient reported his son's school attendance and behavior improved. The patient was more engaged in his own health and treatment planning once his son's needs were met.

## Legal Status

Refugees receive legal status to reside and work in the United States upon arrival. Refugees are very aware of the need to secure more permanent legal status when they become eligible, including permanent residency status after one year and citizenship status after five years. Neither the permanent residency nor the citizenship application processes are simple for many refugees to complete without assistance. Refugee patients with difficulty concentrating or poor memory, both symptoms of PTSD and depression, report significant worry about their ability to take the citizenship test. Physicians and clinical psychologists play a critical role in assessing medical certification for disability exceptions when patients are unable to learn basic English due to physical or mental health symptoms.

Other common legal concerns that arise are related to family law, housing (discussed further below), traffic violations or accidents, family reunification, supplemental security and disability income applications, and domestic violence.

## RECOMMENDATIONS

Know what legal services would be appropriate referrals for your patients. Become aware of the free or low cost legal resources in your area that provide reputable service. Local legal aid services are a great first resource. When providing a referral, be sure that the agency to which you refer your patient will do quality work and not take financial advantage of the patient. One primary care clinic that CVT partnered with recognized the relationship between legal services and health, and they embedded legal aid within the clinic to better serve patients. Consider such partnerships including an on-site legal clinic at your primary care clinic. As permanent residency and citizenship processes become increasingly complex, patients need to be linked with legal resources to complete the citizenship process, particularly when the patient does not speak English and/or if the patient has even a minor criminal record. Physicians and mental health providers can partner when appropriate to complete waivers for patients needing a comprehensive assessment for citizenship or asylum.

### EXAMPLE

A patient had applied for citizenship after living in the United States for five years. She was preliterate in her own language and had a history of memory impairment. She had met with another provider to complete the medical waiver form, and she was denied during the citizenship interview due to missing information on the form. This led to the patient presenting with a depressed and anxious mood. Additionally, she missed work all week due to worries and concerns about the citizenship process. The CVT providers consulted with the primary care provider, who agreed to complete an updated waiver form. During the second interview, the waiver form was accepted. Finally, she received citizenship, which helped her establish a sense of safety and security in the United States.

## Housing

Housing is a critical element of stability. Approximately 65% of asylum seeker and refugee clients at CVT report they have unstable or unsafe housing when beginning care. As with other areas of stabilization, patients may need support to stabilize their housing before other health treatment goals can be prioritized. Patients with chronic pain often report they stay in a bed most of the day and sleep in the same bed at night. Often this may not be what Western providers would consider a bed, but rather blankets on the floor with no mattress.

Non-English speaking refugee tenants may have trouble independently advocating for their housing needs. Too often landlords take advantage of non-English speaking new Americans who are not aware of housing rights. Residential leases may be nonexistent or inadequate when compared to state or federal housing laws. At times patients are reluctant to share potential abuses of power from the landlord for fear of losing housing without another option available. Common housing issues include inoperable locks, causing fear of strangers coming into their home; other lack of repair follow-up causing leaking, molding, or lack of basic needs including heat or refrigeration; untreated infestations including bedbugs; and unlawfully unreturned security deposits to tenants. Any resident with these concerns would have significant stress. This stress is amplified for low-income patients with mental health concerns including PTSD and depression.

## RECOMMENDATIONS

Providers need to have a basic understanding of their patient's home environment and be equipped to support patients to stabilize housing concerns. Ask questions such as, "Who lives in the home? Is housing stable right now?" "Are there concerns about maintaining housing? Are you able to pay rent?" "Do you feel safe in your home?"

Ask patients directly about furniture needs. While some populations prefer not sleep in beds and it is important to honor personal preferences and choices, providers should help patients access beds when interest is confirmed. There are often programs for low-cost or free beds for low-income patients.

Taking time to help a patient problem solve housing concerns is beneficial for their health. Minnesota has a valuable resource, HOME Line, offering consultations with pro bono attorneys when legal housing concerns arise. Legal aid is also a resource when legal representation is needed for housing disputes. There are often government agencies and foundations that offer emergency assistance to help low-income individuals pay rent when faced with the threat of eviction. CVT social workers regularly call landlords to advocate for patients directly and send complaints in writing when necessary. Be prepared to provide patients resources and referrals to address housing needs.

### EXAMPLE

Providers met with a patient whose housing issues have impacted and increased his physical pain. He disclosed having no bed and sleeping on a floor. Due to unemployment and limited income, he was not able to afford a bed for himself. He also had an ongoing issue with the landlord not making needed repairs. The clinicians assisted the patient by advocating with the landlord and referring him to legal services for representation regarding his housing issues. CVT providers also assisted the patient to manage his stress and depressed mood while obtaining a bed for him through community resources, which helped in reducing his physical pain.

## Transportation

Transportation is an often overlooked barrier to adequate health care. When beginning services at CVT, over 70% of asylum seeker and refugee clients face difficulties finding transportation, with 30% reporting they have no knowledge or access to transportation and over 40% reporting they are reliant on family or friends to provide them with rides. Refugees living in poverty with mental health symptoms face obstacles in learning how to drive and use public transportation. Driving tests are usually conducted in English and a basic level of literacy is required for the driver's permit test. Patients with PTSD and depression symptoms, including memory trouble, are nervous to use public transportation due to fear of becoming lost.

### RECOMMENDATIONS

Assess if your patient is able to get to appointments without medical transportation. It is in health care clinics' financial interest to increase attended appointments since "no shows" are costly to primary and specialty care clinics. If you know that a patient needs medical transportation, which is often covered by medical assistance, take responsibility for ensuring a patient is given the opportunity to make it to their appointment. Other resources may be available as well—for example, CVT connects interested patients to bus tutors in the community as a way to safely learn the public transportation system.

Set up a transportation policy to promote health care access for patients with transportation barriers that considers these questions:

- Who is eligible for medical transportation?
- Who will set up and confirm medical transportation rides?
- Who will intervene if a ride issue arises?
- How can patients be supported to take on managing their transportation over time?
- How will transportation be arranged for specialty appointments referred by your clinic?

### EXAMPLE

CVT providers met with a patient who lost his leg due to stepping on a landmine. He had chronic back pain and difficulty walking because of an ill-fitting prosthetic. The patient's medical provider had referred him to meet with the specialist to re-adjust his prosthesis. However, he missed several appointments due to lack of transportation and difficulty navigating the system. CVT clinicians assisted him with setting up medical transportation to increase his appointment attendance and also advocated for him to get a readjustment. He later attended the appointment with the specialist and received a new prosthesis that fits him better.



## SUMMARY OF RECOMMENDATIONS

- Assess your refugee patient's basic needs as they ultimately relate to your patient's overall health and ability to follow through with your treatment plan recommendations. Assess for safety and duty to warn (suicidality, homicidality, and child abuse.) Ask follow up questions about time to discern if any of the safety concerns raised are happening now or sometime in the past. You may have to ask this question in several different ways. If there is a safety concern, use the same protocols you would for any patient. If police or ambulance need to be called, coordinate with them to reduce triggering a patient; ask them to enter in the back for example.
- Assess for domestic violence. You may have to build trust before a patient will disclose violence. Familiarize yourself with the cycle of violence and local referrals for domestic violence support that are culturally appropriate. Do not instruct your patients what to do or act disappointed if they stay with their partner.
- Assess for important basic needs such as health insurance, income, food access, needs of the family, legal status, housing and transportation. Refer internally if you have social work or other supportive staff to help. If you don't have this, get to know appropriate external referrals.

### CASE EXAMPLE: RESOLUTION

Dr. Green is typing up notes from their encounter from the beginning of this chapter and he notices Paw may have unaddressed basic needs. She has moved recently. Her son is having health problems. Important mail is not getting to her, the kind of official mail that requires a response and creates more barriers if it isn't answered. Dr. Green worries that basic needs might be impacting Paw's ability to prioritize her health and follow her treatment plan. He asks the clinic social worker, Mai, to follow-up with her by phone with an interpreter to see if she needs support:

**Mai:** *Hi Paw. My name is Mai. I'm calling with ABC clinic. I am a social worker, and Dr. Green mentioned you may have some unmet needs I could help with.*

**Paw:** *I do not remember what I talked with Dr. Green about.*

**Mai:** *That is okay; I understand. I have notes from your session with him that you had concerns about your son's health.*

**Paw:** *Yes I do; I do not know what is going on. He has a follow-up appointment this week at a hospital, but I do not have transportation.*

**Mai:** *Of course, I can assist with following up with the provider to arrange transportation. We could also obtain a release from the hospital to consult regarding your son's health and prognosis. Dr. Green mentioned your apartment door does not lock, is that right?*

**Paw:** *That is right. My neighbor asked the landlord to fix it, but nothing has happened for months.*

**Mai:** *I'm sorry to hear that—that is not right and you have rights as a tenant. Could we set up an appointment together this week to review this concern and make a plan together?*

- Paw:** *Yes, that would be great. I'm very scared in my apartment. I am also worried that I have not received mail for my insurance and food support.*
- Mai:** *We can address this together too when we meet. Please bring any paperwork you have about these concerns. I also understand you are nervous you may be fired from your job. That sounds stressful, and I can see how this would impact your health and your family's health; we can plan to discuss this more together as well.*
- Paw:** *Yes, I am very worried about that. My husband cannot work right now, so if I am not working I don't know what we will do. I cannot sleep and do not know what to do.*
- Mai:** *Thank you for sharing these concerns with me. I understand you must feel a lot of pressure and you are doing so much for your family. I am glad you are also meeting with a therapist here at the clinic who can help you manage your stress and help you feel supported through this time. I look forward to meeting with you this week to address these concerns together. I will also let Lisa know that we're meeting in case you want to discuss these concerns with her.*
- Paw:** *Thank you. I will see you at our appointment. Please make sure there is an interpreter and transportation.*
- Mai:** *Yes, we will schedule an interpreter and arrange transportation. I will submit a request for transportation through your insurance company. Would you like me to request a Karen-speaking driver if possible?*
- Paw:** *Yes, that would be great so that I can communicate. Thank you.*

## DISCUSSION QUESTIONS

Following the considerations and recommended practices shared during this chapter and case interactions, consider the following questions to help challenge your learning and integrate these practices into your work.

*Imagine you are in the position of the patient in this case example.*

- › Would you bring up your basic needs to your doctor? Why or why not?
- › What need would you like to have addressed first? Why?
- › If the provider could not help you with your basic needs, where would you go? What considerations would you have in mind when considering where to go for help?

*Imagine you are in the position of the provider in this case example.*

- › What thoughts or feelings arise when you hear about Paw's basic needs that are not being met? How do you respond?
- › Are there opportunities to advocate for other resources within or outside the clinic to support Paw's basic needs?



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# Behavioral Health Interventions

## CHAPTER 6

### CASE EXAMPLE

While Paw has been able to discuss a treatment plan with her health care providers, she finds that she is still struggling. She meets with her psychotherapist, Lisa, who checks in with Paw about both her physical and mental health symptoms.

**Lisa:** *Tell me about your health now that you have been home from the hospital for a few weeks.*

**Paw:** *I take my medicine, but I still feel dizzy. I am so tired. I just stay by myself in my room.*

**Lisa:** *I'm sorry to hear that.*

**Paw:** *I don't think it will ever get better.*

**Lisa:** *When your symptoms don't improve it can be difficult to remain hopeful.*

**Paw:** *I don't think I will be a healthy person again.*

**Lisa:** *I hear how distressed you feel and wonder if we could talk about practices that could help you improve your quality of life. Are you sleeping okay?*

**Paw:** Yes.

**Lisa:** *That's good; I'm glad to hear it. What about physical activity and your diet?*

**Paw:** *The same.*

**Lisa:** *It sounds like the treatments you're being offered right now aren't giving you relief.*

**Paw:** *They gave me medicine at the hospital, and I took it how they told me. I ran out of the medicine that my doctor here at the clinic gave me. It wasn't helping anyway.*

**Lisa:** *So you're still taking the medicine you received after going to the hospital? But you've stopped the medicines you received from your doctor here?*

**Paw:** *Yes. I can't read the instructions or call the number on the bottles to get refills, and my friend hasn't helped me in understanding what they say. I just stay at home all the time now.*

**Lisa:** *It sounds like you may actually be confused about how to take your medicines and your friend has been helping. But now that you've been feeling worse, you haven't left home, even to get her help.*



**Paw:** *Yes, can you help me with that?*

**Lisa:** *I would like to help with that, and I would also encourage you to reconnect with your friend. Staying connected with friends can be helpful for many reasons, in addition to the help she gave with understanding your medicine.*

**Paw:** *Thank you so much.*

**Lisa:** *Please bring your medicine along to our next meeting, and we will identify any questions or concerns you have that either I or your case manager can assist with directly. I can help identify any questions we might want to you follow up on with either your primary care physician or a pharmacist.*

## Introduction

In integrated behavioral health, it is important that all providers appreciate the interconnected nature of thoughts, feelings and physical health. This chapter focuses on ways all health care providers contribute to this perspective to help refugee patients feel whole again. Behavioral health interventions are often a primary source of stability for patients and can be a first step towards building a strong foundation for the future.

Specific trauma treatment methods used by behavioral health specialists, such as prolonged exposure therapy, EMDR, Narrative Exposure Therapy or other psychotherapeutic modalities are outside this toolkit's scope and will not be included in this chapter. However, these and other psychotherapeutic approaches may be useful for providers to have a basic understanding of so they can describe them to patients as potential treatment options.

The recommendations of this chapter are meant to be applicable in any integrated behavioral health setting regardless of the specific psychotherapy modality used. This chapter will describe key elements of behavioral health interventions that are important in offering holistic care to refugees. At times, we will focus on the specific role a behavioral health specialist may play, but many aspects of this care can also be provided by other members of the health care team. We encourage all providers to examine ways that their role could incorporate these practices.

Behavioral health specialists include professionals from various disciplines, including psychologists, clinical social workers and licensed counselors. Physical and mental health concerns have strong overlap. As such, it is important for the behavioral health provider to consult with medical providers. The example of Paw illustrates how health and language literacy are barriers to taking medication, despite efforts to take them correctly. The behavioral health specialist plays a key role in understanding how the patient's mental health symptoms, medical conditions, and social context create barriers to accessing and implementing a quality care plan. The following are behavioral health care recommendations are applicable to all providers in the primary health care setting.



## Establishing Trust

In her book *Trauma and Recovery*, Herman (1992), describes basic elements necessary for recovery from traumatic experiences, the principle one being the establishment of trust. The recovery process requires healing relationships. She notes that empowering the survivor is “the first principle of recovery” (p. 132), and emphasizes that even a patient who arrives at the clinic in a state of helplessness or is a danger to herself or others, “should still be consulted about her wishes and offered as much choice as is compatible with the preservation of safety” (p.134). When this principle is applied to integrated care, behavioral health specialists may be required to expand traditional ideas of therapy and take on additional responsibilities. Examples of this include scheduling appointments, consulting with physicians, follow up on referrals and medications and reviewing treatment instructions in session.

Empowerment is an essential component to trust building in an integrated care model. With patients who have a high level of need, it is easy to take on the role of “helper” and make choices on behalf of the patient. Traumatic experiences are inherently disempowering and take power away from survivors. Therefore, when a health care provider is able to provide and respect choices, this contributes to the trauma recovery process.

## RECOMMENDATIONS

Trust-building opportunities can come in many different forms in integrated care settings. Trust can begin from the very first interaction with a patient, including an initial phone call to schedule an appointment or a first meeting. Taking the time to introduce oneself slowly and explain your role in practical terms can ease anxieties about the appointment and create a foundation of understanding. Trust building can then be incorporated across interactions with clients, from the informed consent process to ongoing care. Trust is often a long-term treatment goal rather than an initial stepping stone in therapy with war and torture survivors.

### EXAMPLE

Many refugee mothers at CVT express interest in birth control. While this interest is there, many of these refugee mothers also said their doctors told them what birth control option they would be administered, with little consultation about options, effectiveness, procedure or drawbacks of the approach. Many of these mothers, when learning of their choices during mental health meetings, identified values and interests that were at odds with these approaches, with many feeling more empowered and returning to their medical providers requesting different forms of birth control. This experience of empowerment garnered greater trust for their health care providers.

## Obtaining Informed Consent: The Foundation for Trust

Informed consent for treatment is an ongoing, living process when working with refugee communities. Western medical services, particularly mental health, may be new and unfamiliar to a refugee patient. While obtaining consent to treat happens from the first appointment, providers can expect that a patient may need to “give it a try” before deciding if they are interested in the service.

### RECOMMENDATIONS

Actively remind patients that it is their choice to participate, and they can end services at any time if they decide they are no longer interested. Assess for subtle communication that a client may not be interested in services, such as frequent no-shows unrelated to logistical problems, or requesting to end appointments early on a regular basis. Checking in throughout the course of treatment about how services are going allows providers and patients to negotiate consent. Deciding to open up past traumatic experience takes a great deal of vulnerability; when providers engage in an ongoing consent process it helps to ensure that disclosure is on the patient's terms.

### EXAMPLE

An elderly Oromo patient arrived for her first psychotherapy appointment but did not know why she was meeting with a new provider. When the psychotherapist explained the service and asked the patient if she wanted to engage in therapy, the patient stated, “You know what I need.” The therapist, worried about the patient's ability to consent to therapy, asked how she was referred to therapy. The patient said, “My doctor told me to come.” The therapist then asked the patient about common life struggles for refugees such as worrying too much, having unwanted memories of bad experiences, feeling tired or tense. The patient said that she experienced all of those things, and the therapist was able to talk with the patient about how they could work together in psychotherapy to address those feelings and worries. The patient then agreed to continue to meet with the therapist again.

## Showing Interest in a Patient's Cultural Background

Additional trust building can occur when a provider shares a basic understanding of the sociopolitical conditions that have led refugees to relocate to the United States. The very act of seeking rehabilitation is political. When a refugee patient who has experienced politically motivated violence or torture comes to seek care, they are standing up to their oppressors and breaking a collective silence. The right to rehabilitation is a recognized human right. However, refugee patients often describe worrying that their experiences will be “too much of a burden” or “too different” from their providers' experiences.



*A Hmong Story Cloth depicting a refugee experience*



## RECOMMENDATIONS

Express interest in your patient's life before coming to the United States. As refugee communities have high rates of torture and war trauma, learn about conditions of the patient's native country from the patient if they want to talk about it. However, don't rely solely on the patient for this information. Demonstrate curiosity about your patient's experiences and show them that you can understand and tolerate hearing about their problems. Take the time to listen to past experiences to build trust and to serve as a witness to gross human rights atrocities.

### EXAMPLE

A Liberian woman met with a psychotherapist for the first time on the recommendation of her primary care doctor. The woman immediately informed the therapist, "I am not crazy." The therapist validated this and shared knowledge of the horrible experiences of many Liberians during the wars. The therapist talked about impact of war for people, including ongoing fear, difficulty trusting others, having uncontrollable memories and wanting to isolate from others. The patient asked, "How do you know about me already?" The therapist talked with the patient about how these are common for many war trauma survivors and that they are the body and mind's natural reaction to horrifying circumstances. The patient reported feeling relief that she was not alone and that the therapist had knowledge of experiences like hers.

## *Considering Room Setup*

If behavioral health staff are on site, what does their space look like? Do providers have their own permanent office or do they move from office to office where space is available? In one CVT clinic, clinicians see patients in exam rooms. It has been necessary to move exam tables, swap out explicit medical displays, and change lighting sources in the room. For all health care providers, it can be helpful to address components of the office space that could be uncomfortable, distracting, or even triggering for patients.

## RECOMMENDATIONS

- Find ways to make your office as comfortable as possible. For example, some refugee patients are not tall enough to have their feet reach the ground when sitting in office chairs. Having a foot stool or pillow available can help a patient feel more comfortable during the appointment.
- Allow for breaks when needed during appointments. This can be especially helpful for long appointments or when assessing for traumatic experiences. Breaks can allow patients to collect themselves and keep going.
- Have snacks and drinks on site for patients. Some patients may travel a long way for appointments or may lack access to food. Having snacks can help clients feel more comfortable and able to talk.

### EXAMPLE

At one primary care clinic that sees a high volume of refugee patients, staff decorated for Halloween. Decorations included skeletons and graveyards. Refugee patients who had experienced war and seen dead bodies arrived at the clinic and quickly became triggered to their past traumas. Mental health staff sensitive to trauma recognized the issue and raised it to clinic leadership. The clinic worked to remove decorations that might be scary or triggering and replaced those with something more neutral such as pumpkins and fall leaves.



## Defining Psychotherapy

Refugee patients from differing cultural backgrounds will have various levels of understanding of mental health services. Some countries have highly developed infrastructure for mental health services, and patients may have pursued treatment with a psychotherapist or psychiatrist before coming to the United States. However, in some contexts mental health is highly stigmatized, and there may be a lack of mental health referrals in the home community. In some countries the mentally ill are kept in prison-like conditions and subjected to restraints, painful rituals or violence as forms of treatment. Furthermore, health clinics and community centers may have been damaged or destroyed in wartime situations. In these instances, access to emergency mental health care may be limited or nonexistent until a refugee patient gets to a secure location. These factors make explaining psychotherapy a particular challenge. Providers are tasked with the responsibility of explaining services while mitigating stigma and remaining sensitive to a patients' psychological wellbeing.



### RECOMMENDATIONS

- Ask patients whom they would go to in their country when they are having problems (e.g. like when they are feeling sad, worried, scared, having interpersonal problems or other conflicts). Acknowledge these resources, whether medical or traditional, and frame psychotherapy as an example of how people access help in the United States.
- Ask patients if they have had experience with psychotherapy in the past. Don't assume they have not.
- Explain what mental health services can address using concrete examples—for example, feelings of sadness, difficult memories from the past, difficulty sleeping, feeling nervous or afraid, difficulty adjusting to life in the United States, or worries that won't go away no matter what you try.
- Be open and explicit in naming the complementary, interconnected nature of many health problems and treatments. Patients may present with medical concerns or chronic pain that is related to past traumatic experiences or mental health. Be fluid in using language about the body and emotions.
- Be aware of power dynamics when making a referral. Refugee patients may defer to doctors or trusted medical providers to make recommendations. It is important to weigh benefits and risks and promote choice when possible.

## Encouraging Treatment Plan Adherence

In most primary care settings, physicians and nurses have limited time to meet with a patient; appointments may occur on a monthly or quarterly basis. For mental health providers, the frequency and intimacy of contact is often much higher. Given this level of intensity, more details about social circumstances and health histories are likely to emerge in behavioral health sessions. Also, behavioral health appointments allow more time for exploration. For example, CVT clinicians have had many experiences of patients reporting to their physician that they are taking their medicine. However, when asked to describe exactly how these medicines were being taken, major errors, misunderstandings and overdosing were revealed.



## RECOMMENDATIONS

- Because there is often more time in behavioral health appointments than in other medical appointments, behavioral health providers can ask more about follow through with treatment plans and medication regimen adherence. See Chapter 8 for more about concerns with medication regimens.
- Behavioral health providers should not step beyond their professional competence when interacting with medical treatment plans. When medical concerns are raised during a mental health appointment, providers need to use this as an opportunity to collaborate with medical providers to address issues and adjust treatment needs.
- Medical and mental health providers need to communicate regularly. For example, many electronic medical records systems have messaging components. This is a fast and efficient way to share information and consult on the spot. If possible, regularly schedule a multidisciplinary consultation meeting for in-depth consultation that allows providers to decide how to approach health concerns from a holistic perspective.
- Construct and communicate unified recommendations. Each person in the care team needs to work to ensure that they understand treatment recommendations and can communicate those across the treatment team.

### EXAMPLE

A woman with osteoarthritis of the knee was recommended to forego knee replacement surgery and lose weight in order to experience less severe pain. As she simultaneously had a mood disorder and traumatic losses, she struggled with this recommendation. She did not know how to advocate for herself and articulate how the pain she was in was so debilitating that she could not participate in the recommended exercises that might help her lose weight. With the support of a social worker and psychotherapist, she learned about chronic pain management. She found ways to educate herself about her problems and developed a better understanding of medications and best practices for taking them (in combination with other mental health treatments). She could then take steps toward participating in both the physical activity and community activities that sustained a realistic treatment approach for her. She experienced considerable relief, and while she was not cured of her pain, she was far more engaged in a way that raised her quality of life in multiple domains.

## *Addressing Chronic Trauma*

Most refugee patients have survived multiple overlapping traumatic events. Base rates for war trauma and torture are high among resettled refugees (Higson-Smith, 2015). Many refugees have lived in the midst of ongoing threat and have not had opportunities to integrate or grieve the multiple losses incurred in their lives. Higson-Smith (2013) describes the concept of continuous traumatic stress and helps identify examples of this stress in torture survivors' lives. While one could argue that life in the United States is in general safer and more stable than life in a country at war, it is important to assess ongoing threats to safety that can undermine a felt sense of safety and stability in the recovery process. For example, many refugees continue to feel unsafe because they are experiencing poverty that includes substandard housing or living in an area with high rates of violence. Additionally, refugees often face experiences of racism and other forms of xenophobia.

## RECOMMENDATIONS

- Don't shy away from the trauma. Research shows that refugee patients want to be asked about their past trauma experiences if it would be beneficial to their overall health. Do not assume that your patient has a trauma history, but hold on to this possibility and be open to discussing the past to get a full picture of a patient's health.
- Assess for factors in the patient's current environment that could be triggers for past trauma, such as loud noises or an unsafe neighborhood. Openly discuss triggers with your patients. For example, your clinic may consider providing education on fireworks on the Fourth of July for patients who may be reminded of bombings in their home country.
- You can inquire about past traumatic experiences without taking the responsibility to treat the trauma. Containment is an important aspect of working with traumatized patients. Discuss the trauma enough to gain an understanding of its impact, and make a referral to mental health services for more extensive assessment. Phrases to help with containment include the following:
  - › "I'd like to ask you a little about experiences you might have had in the past. We won't go into detail today, but it is important for us to understand what you have lived through so we can make a plan for your health care."
  - › "I understand many people who have come to the U.S. from your country have lived through a war. You don't have to tell me everything today, but I am wondering if you have lived through the war or other difficult experiences."
  - › "Thank you for telling me about your experiences. I can see they are very painful. We won't have time to talk in detail today, but I'd like to help you make an appointment to a provider who can talk with you in detail and offer additional support. Would that be okay?"

### EXAMPLE

A refugee patient was meeting with a psychotherapist, social worker and physician on a regular basis. She continued to report feelings of fear and waking up with a rapid heart rate. She was prescribed a sleep medication from her doctor and was open with her psychotherapist about her past war trauma. Week after week the patient continued to report high levels of symptoms associated with PTSD. Her social worker inquired about her housing during an appointment. The refugee patient disclosed that she recently moved to a new neighborhood because her family was having trouble paying the rent. The neighborhood is dangerous and they do not feel comfortable leaving the house after dark. She describes hearing gunshots and people fighting at night, which reminds her of the war. She is unsure what to do if she finds herself in danger, as she has never called 911 before and does not speak English. The social worker began working with the patient to help her understand her rights and develop skills in using emergency services while exploring other options for housing. The psychotherapist began working with the client to manage triggers and develop a plan for engaging safely with her community. These complimentary approaches addressed past and present traumatic threat.

## *Advocating for Patients*

Health care environments are fast-paced, and every provider is busy throughout the work day. This makes debriefing and consulting during the day a particular challenge. When working in an integrated model across different specialties, it can be challenging to find the time to make recommendations and follow up about a patient's overall plan. For new Americans navigating the complicated U.S. health care system, advocacy from behavioral health providers to increase their service access and safety needs can be a vital source of support, resources and empowerment; it also builds trust by clearly establishing the non-neutrality of the provider when it comes to the patient's health and welfare.

## RECOMMENDATIONS

Every provider involved in a patient's care needs to see themselves as an advocate. For mental health providers with expertise in trauma, this often means bringing knowledge about a patient's past experiences to the attention of other health care providers and working in collaboration to advocate for a patient's needs. For medical providers, this can mean advocating with an insurance company to cover the cost of supplements, such as Ensure or other vitamins, when a provider knows a patient is living in poverty or has experienced deprivation during war or while fleeing.

Follow-up care can sometimes span the course of many months and can involve many different medical providers. The mental health team might have the most frequent and ongoing interactions with a refugee patient. Working as an advocate for patients when their treatment recommendations are no longer working well is an integral part of the role. One example of this is use of psychotropic medications, such as those commonly prescribed for sleep or PTSD.

### EXAMPLE

A patient from East Africa told his primary care provider that he was experiencing nightmares from his experiences during the war, and that he was often fearful during the day so he was staying home most of the time. The patient told the provider that he wanted a medication to make the nightmares go away. The provider talked with the patient's physician about the issue; the physician agreed to prescribe a sleep medication and described it as a medication to use only until the patient's body could recover to a state where he could sleep on his own. The provider recommended that the patient see a psychotherapist to help with this recovery process. The patient agreed to try the medication in combination with psychotherapy. After six months of treatment, the patient requested to stop taking the sleep medication, as he felt more able to manage his sleep using skills from psychotherapy.

## *Assessing Pain*

For many refugee patients, inadequate health care and injuries sustained during torture, war experiences and fleeing often result in chronic pain. Few patients are instructed in the important differences between treatments geared toward either acute pain or chronic pain, respectively. This distinction needs to be clear for patients to receive accurate recommendations as well as adequate instructions to help them carry out these recommendations. This problem warrants special attention, as so few refugee patients are offered a valid assessment of their experiences and the course of treatment they might expect.



## RECOMMENDATIONS

Many resources exist that can help health care providers better understand the bio-psycho-social dimensions of chronic pain (Williams, 2013). Consulting such references and validating the experiences that have left the patient in a state of chronic pain can be among the more powerful ways to acknowledge the extent of this pain while helping to orient the patient towards successful treatment strategies.



## SUMMARY OF RECOMMENDATIONS

- Trust building is at the core of trauma work. This occurs over time and starts at the first meeting. Treat informed consent as an ongoing process, co-construct meaningful explanations of behavioral health care with patients and let patients know that behavioral health care is voluntary. Express interest in a patient's home country and take time to learn about country conditions.
- Create a welcoming space for patients for behavioral health sessions; allow for breaks; have snacks available.
- Assess if patients have had previous experience with psychotherapy. If they have not, offer a concrete explanation, using examples.
- Behavioral health providers often have more time than medical providers with patients. Assess for treatment plan and medication adherence. Communicate your findings to medical providers.
- Ask about past trauma, assess for current triggers and use containment strategies.
- Advocate for patients within the busy clinic and with external services such as insurance providers.
- Assess for pain, validate the experience and learn more about the bio-psycho-social aspects of pain.

### CASE EXAMPLE: RESOLUTION

A week after Paw's psychotherapy appointment discussed at the beginning of this chapter, Paw brings her medicines to the next appointment.

**Lisa:** *Thanks for bringing your medications today. I would really like to make sure that you clearly understand the role of medicine and understand the purpose of skills we've been working on together.*

**Paw:** *Thanks for helping. I get overwhelmed, confused and don't know what to do.*

**Lisa:** *I know that this might feel overwhelming right now. I know you're doing what you can to improve your health, and I appreciate your openness to working together. Is it helpful to review the medicine together?*

**Paw:** *I think so. I often forget the questions I want to ask my doctor. It would be helpful to write those down together today.*

**Lisa:** *That sounds great. We will work on this together and I can provide an update to your doctor in preparation for your next appointment*

**Paw:** *Yes, I just get so worried I don't do it right.*

**Lisa:** *I hear your concern. Let's take a moment to help you experience a sense of calm again, so that we can return to reviewing your medications when you are not feeling as worried and overwhelmed.*

**Paw:** *I really have benefitted from the breathing practice we have done together. Can we do that now?*

- Lisa:** *That sounds quite helpful. I can guide you through this practice. What preference do you have for keeping the lights on or off?*
- Paw:** *I like them off; the bright light hurts my eyes.*
- Lisa:** *Okay, I will turn the lights off. What preference do you have for listening to calming sounds as we practice breathing today?*
- Paw:** *I like the sounds of the river flowing that we have listened to before.*
- Lisa:** *Great; I will turn that on. Now, find a posture that allows your bone structure to support your body's weight, while you purposefully relax any muscles you find that are tight or tense. Let's begin with a breath of four counts in through your nose. Hold your breath for a brief moment. Now, breathe out through your mouth slowly, as if blowing on a candle that you want to flicker but not go out. At the count of seven, we will return to breathing in through your nose. [They continue in a similar fashion for about five minutes.]*
- Paw:** *I am feeling much better now. Thank you for teaching me how to breathe like this.*
- Lisa:** *I'm so happy we found a way to help you feel relieved like this. Have you been able to practice these strategies at home?*
- Paw:** *Not really, I am so tired I forget when I am at home.*
- Lisa:** *Last time we talked about sleep, diet and exercise. You mentioned things were going okay with no changes. How much sleep do you receive each evening?*
- Paw:** *I go to bed at 10 p.m. and fall asleep around 2 a.m., then I wake up around 6 a.m.*
- Lisa:** *Thank you for clarifying. Have you been getting four hours of sleep per night for a long time?*
- Paw:** *Yes, for a long time. During the war I often needed prepare things for my family and keep watch during the night. I have not needed as much sleep since then.*
- Lisa:** *It sounds like you did an amazing job taking care of your family and keeping watch for your community during a very difficult time. I would like to talk more about these experiences. It seems your body learned how to take care of itself with less sleep during this stressful period. I would like to help find ways for you to increase your sleep slowly since this will likely help your fatigue and other symptoms significantly*
- Paw:** *Yes, I would love to have more energy. That sounds like a good plan.*
- Lisa:** *Okay great, thank you for sharing this information with me today. I am excited to work on these aspects of your health and wellness together. Let's return to those medications again.*

*The discussion about medications will be continued in Chapter 8.*



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## DISCUSSION QUESTIONS

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*Imagine you are the provider working with Paw:*

- › Are there ways of asking about basic health behaviors (including sleep, diet and exercise) that could elicit more accurate responses?
- › What helps guide your decision making regarding what you need to take on as a provider for a patient without acting outside of your role? Can you think of examples that illustrate your decision making during grey areas?

*Imagine you are the patient:*

- › What is helpful to you about this interaction with your psychotherapist?
- › How do you imagine you would feel about your treatment? What will you be looking for in your next session with either your psychotherapist or primary care physician?

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# Working With Interpreters

## CHAPTER 7

### CASE EXAMPLE

Paw returns to her clinic for a medical appointment with her primary care physician. The appointment was scheduled as a routine visit to address Paw's headaches. This example includes the interpreter's dialogue, spoken in Karen and English. In this dialogue, the translation is in English unless otherwise noted.

- MD:** *I am glad to see you here today. I've been receiving updates from your social worker and psychotherapist. That is great you have been attending appointments with them.*
- Interpreter:** *The doctor is glad to see you today. He has been talking with your other helpers, a... [interpreter speaks directly to MD] You said psychiatrist and social worker?*
- MD:** *Psychotherapist and social worker.*
- Interpreter:** *[Turns again to patient] A "psychotherapist" and "social worker" [these words do not have direct translations in Karen so interpreter says each word in English].*
- MD:** *How have you been feeling?*
- Interpreter:** *The doctor asks how you have been feeling.*
- Paw:** *Just like this. Sometimes good; sometimes bad. My heart is beating very fast and I feel dizzy.*
- Interpreter:** *She said she is doing the same, sometimes good and sometimes bad. She feels dizzy and has high blood pressure.*
- MD:** *I'm sorry to hear that. I know last time we met you were feeling stressed regarding your family's financial stability. How has this been going?*
- Interpreter:** *The doctor is sorry. He said the last time you met you were stressed about your family finances. How are you family finances now?*
- Paw:** *I think a little better. My county financial worker called and I need to call back to have my phone interview to continue food stamps. [Directed towards interpreter] Can you help me?*
- Interpreter:** *[In Karen] Yes, I can take you to the county office this afternoon before the*



*community event. [In English] She said she her finances are a little better and she is reinstating her food support benefits.*

**MD:** *Okay great. I also see here that you did not come to our last appointment. Was there an issue with transportation?*

**Interpreter:** *He said that is good. He is asking why you did not come to our last appointment.*

**Paw:** *My child was sick so I had to stay home. I tried to call and cancel but there was no interpreter.*

**Interpreter:** *She said her child was sick so she stayed home. She said she tried to call and cancel but there was no interpreter.*

**MD:** *That's okay, we understand. I hope your daughter is feeling better. Please try and call in to let us know. We do not have interpreters when people call in, but you could ask a friend or family member to help you if you do not have an interpreter to call.*

**Interpreter:** *He said he understands and he hopes your daughter is feeling better. He would like you to find a way to call and cancel by asking a friend or family member to help. I will also give you my phone number later and you can call me so I can help you cancel when you need.*

**Paw:** *Okay, thank you.*

**Interpreter:** *She said she understands.*

**MD:** *Thank you, I will now take your vital signs and do a checkup.*

**Interpreter:** *He said thank you and he will now check your breathing and give you a checkup.*

## Introduction

*Working with interpreters for refugees in integrated care settings is common, yet few providers have had opportunities for formal education and training to develop skills in doing so. The quality of communication and care for patients depends greatly on provider's ability to develop relationships and work closely with interpreters. This chapter explores the skills and relationship building with interpreters necessary to help provide high quality care to refugee patients.*

## The Importance of Professional Interpreters

Interpreters play a key role in medical and mental health appointments with non-English speaking refugees. As of 2012, the Agency for Healthcare Research and Quality found that at least 8.6% of the U.S. population was at risk for adverse events because of barriers associated with their language ability (2012). Furthermore, having access to professional interpretation is a right in many situations. Agencies and providers that receive federal money, including medical assistance reimbursement, are required to give free access to an interpreter for non-English speakers under Title VI of the Civil Rights Act of 1964. A professional interpreter is defined as "an individual who has been assessed for professional skills,



demonstrates a high level of proficiency in at least two languages and has the appropriate training and experience to interpret with skill and accuracy while adhering to the National Code of Ethics and Standards of Practice published by the National Council on Interpreting in Health Care” (National Council of Interpreters in Health Care, n.d.).

Even though this right has been long established, there are challenges to obtaining a professional interpreter in certain settings, such as when a patient is a member of a language group with a small population. In situations like these where interpreters are not available, patients’ children are sometimes called upon to interpret for their parents. This creates both ethical and practical dilemmas. One known danger is that patients may not disclose important or pertinent information when a child is present, and this situation places the child in an inappropriate role given their familial relationship to the patient. Lawsuits can arise when professional interpretation is not provided.

Patients all too frequently fall through the cracks of the U.S. health care system due to interpretation barriers. Trained in-person interpreters are worth the cost to provide patient-centered care.



## RECOMMENDATIONS

Use professional interpreters for your appointments. An in-person interpreter is best; use a telephone interpreter service as a second choice. Do not use children and family members as interpreters. Consider the following questions in your setting:

- Do all staff members know when and how to access an interpreter? Do staff members ever use family members to interpret, even for small items?
- When does a patient speak “enough” English to not use an interpreter?
- Are there requirements for using in-person interpreters compared to phone or video services?

## *Hiring Interpreters Directly*

Frequently medical appointments have interpreters assigned through an external interpretation agency. This service can assist with finding available interpreters in a short time frame. However, relying on outside interpreter agencies has many limitations. One major drawback is that it can be especially difficult to have a consistent interpreter for a patient when an outside agency is used. Patients may prefer to have a consistent interpreter instead of a different interpreter at each appointment. This is particularly important for mental health given potential stigma and the intimacy of mental health services. Patients’ relationships and trust with interpreters often grows over time. Similarly, providers’ and interpreters’ trust and relationships can develop through ongoing appointments.



## RECOMMENDATIONS

Directly hire interpreters when possible. CVT has found that hiring interpreters directly results in increased opportunities to consult with them, learn from them, and address interpretation challenges impacting treatment. Further, hiring interpreters allows providers to offer targeted training to interpreters and hold meetings between providers and interpreters to facilitate collaboration.

## *The Basics of Communication Via an Interpreter*

A survey in 2006 found that 50% of resident physicians reported no training on adapting communicative strategies when working with an interpreter, and 67% reported no training in how to manage situations when they suspect an interpreter has misinterpreted (Hsieh, 2012). These statistics underscore the breakdown in communication that can occur for refugees seeking equitable health care. This section reviews some basic approaches that help providers when communicating through an interpreter.

There are three basic expectations for communication with a professional interpreter: accuracy (i.e., the meaning of everything that is said in the room is correctly expressed), completeness (i.e., the interpreter does not leave out parts of what the patient or provider says), and professional neutrality (i.e., the interpreter refrains from adding or introducing pieces of information, judgments, advice, biases, conclusions, etc., except when clarifying to both the patient and provider that they are doing so for the purpose of helping the two understand one another or when asked by one party to do so).

### **RECOMMENDATIONS**

- Set up your office or examination room in a way that allows you to face the patient directly throughout the appointment. The interpreter should be positioned to the side of the patient or provider so as not to interfere with direct sight of body language and eye contact between the patient and provider.
- Actively listen and observe the patient throughout the session, even when you do not understand the language being spoken. The patient's body language, tone and affect provide a wealth of information, and providers will be more able to notice potential discrepancies in communication and follow up accordingly. For example, if a provider observes a patient with a flat affect speaking slowly, but the interpreter quickly interprets in a happy tone that the patient is doing well, this discrepancy presents an opportunity for the provider to inquire about what they are observing.
- Inquire about discrepancies when the interpretation of what you or a patient says is significantly shorter or longer than the original report. Interpreters may summarize information provided by patients to save time. This practice can cause challenges in treatment. For example, an interpreter may try to guess what a patient is trying to convey when statements are disjointed or incoherent.
- Remind interpreters to interpret exactly what the patient is saying, even if the interpreter cannot fully convey meaning due to linguistic differences. It is the provider's responsibility to follow up with the patient accordingly and seek clarification.
- Do not use the time when interpretation is taking place to direct your attention elsewhere, prepare for the next question or take the next step in an appointment. Staying focused on the patient allows providers to identify cues that can be missed during interpretation. This practice will help your patient stay focused on you instead of the interpreter, allowing you to stay in the role of monitoring the pace of exchanges rather than inappropriately placing that expectation on interpreters. Over time, you will likely understand and look for keywords to support your understanding of the interpretation and potential discrepancies.
- Communicate in the first person and ask the interpreter to do the same. Everything that is said in the session needs to be interpreted, even if it does not appear relevant for the appointment.
- Ask the interpreter to let you know every time they add information during the session, and interpret this instruction for the patient.
- Ask interpreters to be repetitive when patients are repetitive. Sometimes interpreters do not repeat information the

patient has already said, or instead of repeating the information, they say something like “the patient is saying the same thing again.” Remind the interpreter to directly interpret what the patient is saying in the first person since valuable information regarding nuances or why they are repeating themselves could otherwise be missed.

- Address concerns about verbal communications being missed or added directly during the session; this is appropriate to do in the moment. Patients appreciate transparency regarding complete interpretation during the appointment, and this transparency helps both to develop trust and maintain appropriate boundaries.
- Allocate more time for appointments with interpreters. Equity of care requires this, as only half as much information can be communicated in the same amount of time when using interpretation.
- Advocate for patients with interpreters to be treated as any patient would be in your setting. Too often patients needing interpreters have longer wait times to schedule critical appointments due to interpreter scheduling. Patients may be scheduled around interpreters instead of patients’ schedules being prioritized. Review your setting’s procedures on supporting patients needing interpreters to see if there are opportunities for improvements in policies and procedures.

## *Vocabulary Including Idioms of Distress*

Often in health care, mental health, and specialty care settings, a provider uses a word that is not translatable into a patient’s language. Interpreters are then put in the position of interpreting such terms and are left to their own discretion when trying to find an equivalent in the patient’s language. For example, terms such as, depression, anxiety, X-ray and colonoscopy have been described in various, sometimes wildly incorrect, ways when providers have not explained them in more relatable terms. Profound miscommunication and misunderstandings can then occur between the provider and patient.

If you do not modify your language appropriately, interpreters may change the content to make a patient feel comfortable, for example using an idiom of distress when a provider uses a more technical or Western term for depression or anxiety. Providers can lose track of what is actually being said by the patient when interpreters modify content to be more culturally appropriate. Providers need to assume this responsibility to ensure the interpreter maintains a strict interpreter stance.

## RECOMMENDATIONS

- Find and use vocabulary that does not need to be modified for an interpreter to translate. If you are not sure if a word has a translation in the language your patient speaks, ask the interpreter before moving forward (and make sure your exchange is interpreted for the patient as described above).
- Become familiar with idioms of distress and use them to ask patients more about their symptoms. For example, to gain information regarding a patient’s depression symptoms, which were described as a heavy heart, a provider can ask, “You mentioned you had a heavy heart last week. Have you noticed it feeling heavier, lighter, or staying the same?”

### EXAMPLE

A patient shared with her mental health provider that she felt that her doctor did not understand her condition since an interpreter interpreted her concern as “diabetes” instead of “high cholesterol.” Fortunately, this patient knew these key terms in English. The patient did not feel comfortable correcting the interpreter during her medical appointment, but she communicated the error to her social worker, and the social worker followed up with her doctor directly.



- Make sure key medical terms are interpreted correctly and described back to the patient to ensure accuracy. Likewise, use back-translation to check a patient's understanding of what you've said.

### DATA FOR THOUGHT

Interpreters interpret idioms of distress in different ways. In the Healing Hearts study (Esala, Hudak, Eaton, and Vukovich, 2018), CVT staff found four different classifications of how idioms of distress are interpreted: word-for-word "literal" interpretation, contextual interpretation, cultural explanation, Westernization of the cultural expression. Providers are often unaware how idioms are being interpreted. Interpreters are left to use their discretion out of these classifications. This research found that different interpretations for the same expression have significant implications in the clinical setting, including creating shared meaning between patient and clinician, discerning differential diagnosis questions, and understanding the origin of somatic complaints. More information on this research is included at the end of this chapter. Familiarize yourself with idioms of distress common in the populations you see and debrief with interpreters to confirm understanding of how idioms of distress are interpreted.

- Be aware that your interpreter may not come from the same culture as the patient. For example, French, Spanish, Arabic and Swahili are languages that are spoken widely and in many cultures and contexts. A French interpreter from France may not be able to explain an idiom of distress when working with a French-speaking patient from Togo. Work with the interpreter to understand their own level of comfort and skill with cultural mediation, and develop a plan to ensure that you both fully understand the patient.

## Interpreter Roles and Boundaries

Interpreters are often community leaders who know patients outside of appointment sessions. Interpreters may be younger professionals with more experience in the United States than their patients. Nevertheless, interpreters need to stay within their professional role.

## RECOMMENDATIONS

- Facilitate an overview of confidentiality and boundaries with each new interpreter that you and your patient meet. A quick overview is a useful reminder for all three parties, including you, the interpreter and the patient, and it goes a long way in promoting trust and effective communication. Use the guide below in these conversations.

### Orienting Patients to Working with Interpreters

Please feel free to adapt this overview to your unique setting:

1. Interpreters are going to interpret everything said in the room.
2. Interpreters have been instructed that they are not to introduce materials in a session; they only interpret what is said by patient and provider.
3. Speak at a normal speed, but allow time for the interpreter to translate your words. If you pause after every one or two sentences, the interpreter will be able to remember your words accurately.

4. Interpreters are included in our confidentiality agreement. For examples, interpreters are told explicitly they are not to share with anyone outside of the setting that they know the patient through the clinic nor share any content of the session.
5. Ways of communicating: Patients do not call interpreters at home. If the patient needs something, they can call our main line and ask for an interpreter when prompted. If you receive a voicemail prompt, leave a message with your name and phone number very clearly in their own language and the provider will call the patient for details with an interpreter on the phone.
6. Interpreters provide services only at our clinic's appointments. Patients are expected to provide their own interpreters for other needs.

- Ask directly if the patient and interpreter know each other in the community. Patients often already feel stigma or shame in accessing services, and special attention needs to be paid to confirm the patient does not know the interpreter outside of the professional interpreter relationship. A new interpreter needs to be identified when a conflict of interest is present.

### EXAMPLE

A refugee woman patient met with a psychotherapist for four meetings with an interpreter. After the fourth meeting, the psychotherapist asked to meet with the interpreter separately after a session. In this meeting, the psychotherapist shared that he had noticed the woman repeatedly minimize symptoms and even deny symptoms recently reported to her physician. When discussing this observation with the interpreter, the interpreter expressed relief. She shared that this patient was actually a relative and, perhaps, was reluctant to share her concerns due to their relationship. The psychotherapist explained that it would be important to find another interpreter in this situation for upcoming appointments. The interpreter agreed and shared that she wasn't certain whether or not she should speak up about such a situation.

- Call your clinic to see how a non-English speaker would be able to schedule an appointment or speak with a provider. If there are language options, what languages are missing? Would a patient need to navigate through a few menu items in English before an interpreter became available? These seemingly small obstacles severely limit access for many refugee patients.
- Avoid the following scenarios where interpreters are used inappropriately for seemingly good reasons:
  - › A clinic might encourage patients to call an interpreter to set up their next appointment or follow up on a specialty referral.
  - › An interpreter may agree to help a patient set up medical transportation for their medical appointment.
  - › During a session in which a patient reported barriers to attending an outside appointment at an agency such as social security, an interpreter might ask if he or she could offer to pick the patient up and interpret at the appointment.

In these instances, the interpreter becomes involved in the patient's treatment planning outside of the interpreter role and can take on decision making for the patient. The clinic's non-interpreter staff need to maintain responsibility for having procedures in place to fill gaps caused by language barriers. Identifying and anticipating



these gaps ensures an interpreters do not take on other roles, such as supporting logistics or following up and advocating on the patient's behalf. Consider hiring health care navigators, community health workers, or health care home professionals to support patients in treatment planning instead of leaving a gap that interpreters may be asked to fill.

- All communication between a clinic and a patient, no matter how small, needs to be communicated with both a provider or staff member and interpreter.
- When in doubt about the accuracy of communication, call the patient with a different interpreter to ask for feedback regarding appointments, including comfort with the interpreter.

### EXAMPLE

A patient shared that there was an interpreter who visited her home bi-weekly with a nurse who set up medications. This interpreter reportedly yelled at the patient during reminder calls and insulted the patient during appointments. The patient was unable to communicate this concern to the nurse using the interpreter since she would need to voice these concerns through the very interpreter causing the distress. When our clinicians learned of this circumstance, they were able to follow up with the nurse in English to request a new interpreter on behalf of the patient.

- Interpreters should not stay with patients when the provider is not present, to reduce the likelihood that the interpreter is placed in a role outside of the interpreter role. For example, if a patient shares information with the interpreter after a provider steps out, this leaves the interpreter in a position to decide how to respond and what to share when the provider returns. Instruct the interpreter to leave the room when the clinician steps out; they may simply stand outside the door or room where the meeting is taking place.
- Encourage interpreter staff to obtain certificates, attend trainings and develop language skills. We recommend that interpreter ethics be well understood and continuing education be pursued to enhance this capacity.<sup>5</sup>

## Learning from Interpreters

Patients' experiences of illness take place within social and cultural structures, making boundaries between medicine, culture and language hard to define (Hsieh, 2010). Medical providers miss vital information when they don't intermittently request input from interpreters before or after their meetings. Interpreters walk away from appointments with a wealth of knowledge regarding observed miscommunication and expressions that were not appropriately identified by the provider.



### RECOMMENDATIONS

Take time to engage with interpreters and invite feedback to avoid missing crucial information.

## Written Interpretation Versus Verbal Translation

Interpreters are generally only responsible for verbal interpretation during a session; but a provider may see the benefit of providing something written to the patient in their native language. For example, it could be helpful for a patient to leave an appointment with a list of coping strategies or to record their life story when crafted during the course of psychotherapy.

<sup>5</sup> Additional information on interpreter ethics and standards is available through the National Council on Interpreting in Health Care (<https://www.ncihc.org/>).



## RECOMMENDATIONS

- Don't surprise interpreters with requests for written translation during a session; this is outside of the scope of the appointment. Some interpreters are not literate in the language they are interpreting or may not feel comfortable or confident in their writing abilities.
- Ask interpreters about their ability and willingness to provide written interpretation. Engage interpreters on a case by case basis to write small-scale items to support patient's treatment, for example writing a medication's purpose and instructions in the patient's native language. Written interpretation for larger projects or official legal documents should not be requested of interpreters engaged in verbal interpretation appointments.
- If you did not have a chance to have a conversation prior to your appointment about written translation and a need emerges while meeting with the patient for something to be written, ask the interpreter if they feel comfortable writing in their language. Have this interpreted to patient. Offer the interpreter an alternative. For example, "I can also have this translated after our meeting if you don't feel comfortable doing so as an oral interpreter."

### *Specific Concerns for Interpreting in Mental Health*

It can be challenging to recruit interpreters for mental health sessions. The high skill level required coupled with the emotional demands of working with trauma can make it difficult to hire, retain and sustain interpreters. Providers at CVT have heard similar sentiments expressed by interpreters when they have shared frustration in working with patients with memory problems, stating that they find physical health appointments "more straightforward." Additionally, there may be stigma regarding mental health treatment in the target community, including among interpreters.



## RECOMMENDATIONS

- Orient interpreters you don't know or who have not interpreted in mental health settings. Discuss how validation and empathic statements will be interpreted. For example, the clinician might say something like "You're sad" after a patient has stated something similar, but those statements are sometimes not interpreted. This validation or reflection of understanding serves a vital role in mental health work. It is imperative that these simple verbalizations be interpreted even if it seems like the clinician is just repeating what the patient is saying.
- Address the topic of silence proactively with interpreters. Silence can be a regular part of mental health appointments. Silence can also cause more anxiety and lack cultural reference points as part of a health care service. Explain to interpreters that silence can be used purposefully as a therapeutic tool or simply to give the patient choice as to when to speak. Normalize that patients may become quiet or respond minimally and ask that interpreters allow this silence to happen.
- Prepare interpreters before introducing practices such as mindfulness, breathing or meditation techniques and exercises, as it may lead to purposeful moments of silent relaxation during which both the interpreter and clinician need to refrain from noise and movement.
- Encourage and coach interpreters to be as cognizant as possible of body language that is natural when in the presence of feelings such as anxiety and helplessness. Clinicians and interpreters need to develop and use their own coping strategies to remain calm and present.



## Risk Assessment

For behavioral health risk assessments, inform interpreters that during a suicide assessment a clinician will ask very direct and concrete questions that must be interpreted and not summarized. Interpreters may switch in and out of first person to third person unconsciously. This may be a sign that the content is distressing for the interpreter. Ask interpreters to let you know if they are switching to third person if what is being said is too difficult to tolerate.

It's important that interpreters provide all information reported by the patient to the clinician. Risk assessments can make interpreters and clinicians feel anxious. It is normal for interpreters to want to take care of patients, especially during a risk assessment when a patient can become clearly uncomfortable. Name the difficult position interpreters are in, and ask that they continue to interpret only what is said between patient and clinician.

Clinicians need to be mindful of the interpreter's schedule, including during a risk assessment. Clinicians need to find another interpreter or use a phone interpreter as a last resort if no interpreter is available to continue the risk assessment. Don't leave interpreters with patients without the clinician present during a risk assessment.

Invite interpreters to be part of conversations with the paramedics as an integral part of the treatment team. Discuss concerns interpreters may have about seeing individuals in uniform and equip interpreters with coping strategies prior to conducting risk assessments as appropriate. Following a session with a risk assessment, the clinician should invite the interpreter to debrief. The interpreter can also request this meeting.

## Secondary Trauma for Interpreters

Interpreters can be members of the patient's target community and may have experienced war trauma or torture directly or indirectly. Interpreters may share with providers that the trauma discussed during a session happened to them or their families too. Interpreting can be an isolating role, and interpreters often hear and interpret difficult life experiences and situations without holding a more permanent role in the patient's ongoing care. Unfortunately, given the logistics of interpretation work across multiple medical settings and clinics, interpreters are often excluded from more informal staff support opportunities and wellness activities (more information on organizational wellness, self-care and secondary trauma is discussed in Chapter 10).

## RECOMMENDATIONS

- Consult or debrief with interpreters following difficult appointments, just as you would check in with other providers for consultation and support.
- If possible, use the same interpreter with patients in order to help mitigate secondary trauma for interpreters, as there is opportunity to witness ongoing treatment and healing over the course of time.
- Encourage interpreters to request a debrief when feeling overwhelmed or triggered following a session.
- Provide interpreters with training regarding secondary trauma, including information regarding self-care, the benefits of exercising, breathing techniques and debriefing structures and processes.

### EXAMPLE

A provider had been working with a patient and an interpreter for three years. The patient was a single adult male who had a mixed personality disorder in addition to PTSD and depression. The personality disorder greatly interfered with his social functioning, to the extent that he was alienated and isolated from his ethnic

community here and his family back home. Other interpreters who had worked with him in other community settings refused to interpret for him. He had likewise rejected every interpreter he worked with except the one the provider has been using, who is exceptionally patient and accepting. The patient easily felt insulted and treated others in a hostile, aggressive and accusatory manner. He placed responsibility for all that happens on others and was not able to identify or own his feelings or thoughts. After a difficult session in which he was blaming and angry towards the therapist, the interpreter contacted the provider and said that he was “burned out” with this patient. He asked the provider to try to find another interpreter. He explained that he had reached his limit with this patient and that he could not bear to watch the patient treat people who were trying to help in such an ungrateful manner. He further explained that he did this work as a service to his ethnic community (the agency also paid him) but that there was no reward in working with this patient, as the patient showed no interest in wanting to help himself. He said he felt exhausted, tense, and drained after sessions and that he saw no signs that this would change, given the patient’s personality and how difficult it was to be around him. This interpreter was a highly skilled, mature interpreter on whom the agency depended in working with many other patients.

What would you do?

## GENERAL PRINCIPLES IN WORKING WITH INTERPRETERS BEFORE MEETING WITH A PATIENT

### *Don't:*

- Assume the interpreter has experience interpreting for your service type (e.g., specialty appointment, mental health, physical therapy).

### *Do:*

- Develop a pool of accessible, trained professional interpreters for the most common languages spoken in your area of service delivery.
- Review common challenges faced during interpreted sessions. There may be instances where there is conflict between patient and provider. Remind the interpreter to continue interpreting completely and let the parties speak for themselves without taking sides. Interpreters should refrain from injecting their own values, ideas, suggestions and commentary into the discussion.
- Screen interpreters: Determine their level of language sophistication, knowledge of the culture, sensitivity to mental health issues (especially confidentiality), and general disposition for the tasks to be done. For mental health service delivery, it is important to ask about the interpreter’s willingness to do mental health interpretation. Many interpreters have their own trauma history and need to make informed choices about re-exposure to traumatic events.
- Together with the interpreter, determine which groups, backgrounds, languages and dialects would be a “good match” for his or her skills and background.
- Orient interpreters to the organization’s mission, goals, structure, terminology and roles. This is ongoing rather than a one-time effort.
- Develop and maintain good working relationships with interpreters.
- Agree on a nonverbal “stop signal” for the interpreter, patient or provider to use as needed, so a method of polite interruption is cleared with all parties beforehand.



## DURING APPOINTMENTS

### Do:

- Explain your role and that of the interpreter. It is especially important to address the issue of interpreter confidentiality and how the interpreter and patient will handle future interactions within the community (dual, if not multiple, relationships are often unavoidable). Consider using the "Orienting Patients to Working with Interpreters" handout in this chapter when meeting with new patients.
- Remind the patient that the interpreter will interpret everything that is said by everyone present.
- Expect tasks to take longer time when an interpreter is used.
- Expect the interpreter to interrupt when needed for clarification.
- Expect the interpreter to take notes if things get complicated.
- Prepare to repeat yourself in different words.
- Have the parties speak directly to each other, not to the interpreter (e.g., "How are you feeling?" instead of "Ask her how she is feeling"). Make sure the interpreter also speaks to both parties in the first person.
- Look at the patient while you are speaking to him or her, not the interpreter. Maintain gentle eye contact with the patient when the patient or the interpreter speaks.
- Use the interpreter as a cultural broker to avoid unnecessary cultural misunderstanding.
- Pay more attention to your nonverbal communication, which is the only means of direct communication between you and the patient.
- Watch for subtle signs of discomfort or distress as a clue that the interpretation is not going well; watch for large gaps in utterance length between interpreter and patient.
- Be aware of ethnic/age/gender/class differences between the interpreter and patient.
- Use short, simple statements and stick to one topic at a time.
- Be prepared for each appointment
- Regulate the pace of the interaction, pausing in natural places to permit interpretation.
- Check to see if the message is understood (may ask interpreter to repeat things such as instructions/directions back to you in English).
- Encourage the interpreter to tell you when they are having difficulty.
- Ask the interpreter to make a complete interpretation in the event of obvious omission.
- Give the interpreter time to interpret concepts. One word can require a lengthy explanation in either direction if the concept doesn't exist in the other language.

### Don't:

- Use a word-for-word interpretation. Literal translation rarely makes it possible to re-express the original meaning due to the uniqueness of each language.
- Chain questions (e.g., "Do you smoke or drink coffee?"). Ask only one question at a time.
- Say anything you don't want the other party to hear.
- Talk about patients in their presence. If you need to consult with the interpreter, explain what you are doing to the patient.
- Confuse the interpreter by backing up, rephrasing, or hesitating. Don't "think aloud" or use a reflective style that changes, meanders or backs up in the middle and erases parts.
- Talk fast or talk loudly (do not raise your voice as if the patient were hard of hearing).
- Use referents (it, this, that, he, she, they, her, him, anyone, no one) in a new speaking "turn" without clearly defining the referents for the interpreter and the patient.
- Assume your concepts or even language structures exist in the other language (e.g., verb tenses do not exist in Khmer; past versus present versus future is conveyed by the surrounding context rather than the verb; the word depression doesn't exist in many languages).
- Rely on gestures to convey meaning. Only your words are interpreted.
- Tune out or think only of your next question while the patient is speaking, even though you don't understand what's being said.
- Use unexplained idioms, slang, obscure or ambiguous words, abstractions, metaphors, jargon, etc.
- Keep repeating questions that aren't being answered without considering the need to rephrase the question.
- Expect the interpreter to know everything about the patient's culture. Other cultural resources may be needed.



## AFTER APPOINTMENTS

### *Don't:*

- Skip the debrief. The best cross-cultural learning for both providers and interpreters often happens through immediate feedback using specific situations as learning opportunities.

### *Do:*

- Debrief on communication problems. Ask the following questions: "Was there anything you think I did not understand or respond to appropriately (tone of voice, nonverbal communication, etc.)?" "Anything that reflected my lack of understanding of the patient's culture?" "Did you have any difficulty interpreting (accent, dialect, patient not answering the questions asked, specific words or concepts, etc.)?"
- Debrief on emotional and trauma-related issues. As, for example, "Did this bring up any difficult feelings for you?" One could also consider doing this with groups of interpreters.

## SUMMARY OF RECOMMENDATIONS

- Hire professional interpreters. Don't use family or friends.
- Learn the basics of communicating via an interpreter: Set up chairs so that you are looking at patient; watch for excessively long or short interpretations that don't match your length, and address when this happens; and allow extra time for interpreted appointments.
- Avoid U.S. idiomatic phrases or words that are difficult to interpret.
- Support interpreters in maintaining their boundaries and roles. Talk directly with interpreters and patients about confidentiality, and don't leave interpreters alone with patients or ask interpreters to do task with patients when there is no provider.
- Learn from interpreters; check in between sessions when you can to ask about potential miscommunications or cultural context you may have missed.
- Don't expect verbal interpreters to be able to provide written translation. These are two different skills. If you want an interpreter to translate something in writing, ask before the session.
- Directly hire interpreters as staff when possible (versus exclusively using interpreter agencies).
- Address secondary trauma with interpreters between sessions. Ask how interpreters are doing and if they would like to debrief, particularly for difficult sessions.



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## CASE EXAMPLE: RESOLUTION

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Paw returns to see her doctor with a different interpreter a few months following her last appointment. The clinic recently started orienting patients to working with interpreters and has hired interpreters on staff.

**MD:** *Nice to see you today, Paw. Thanks for coming in. Have you worked with this interpreter Htoo Hser before or do you know each other?*

**Interpreter:** *Nice to see you today, Paw. Thanks for coming in. The doctor is asking if you have worked with me before or if you know me.*

**Paw:** *No, I haven't, I do not know her.*

**Interpreter:** *[Interprets verbatim]*

**MD:** *Okay, thanks for letting me know. I would like to review this brief handout together on working with interpreters to make sure we all understand each other.*

*[The provider reviews the Orienting Patients to Working with Interpreters handout included in this chapter. In turn, the interpreter provides an interpretation of each point.]*

**MD:** *Any questions on any of these items?*

**Interpreter:** *[Interprets verbatim]*

**Paw:** *I thought I should call the interpreter when I needed something at the clinic. That is what I have been doing when I need to schedule an appointment.*

**Interpreter:** *[Interprets verbatim]*

**MD:** *Yes, when the interpreter went on vacation last month we realized a lot of people were missing their appointments, so we improved our policy so that you can call the clinic directly and leave a message if a staff interpreter is not available. We will give you a call back with an interpreter.*

**Interpreter:** *[Interprets verbatim]*

**Paw:** *Ok thanks that makes sense. My heart has been feeling very shaky the last month.*

**Interpreter:** *[Interprets verbatim]*

**MD:** *I'm sorry to hear that. Can you describe more what you mean by shaky?*

**Interpreter:** *[Interprets verbatim]*

**Paw:** *It feels loose like it moves around too much instead of staying still.*

**Interpreter:** *[Interprets verbatim]]*

**MD:** *That sounds very difficult. Do you have trouble breathing?*

**Interpreter:** *[Interprets verbatim]*



- Paw:** *When my heart is shaky like that, yes. I am only able to breathe like this [demonstrates shallow breathing].*
- Interpreter:** *When my heart is shaky like that, yes. I am only able to breathe like this.*
- MD:** *Do you notice if your heart feels shaky when you feel nervous or stressed? [motioning to interpreter] Is there a translation for these terms?*
- Interpreter:** *[To Paw in Karen] The doctor asked me about a translation into Karen, I will respond to him about this first and then interpret his question. [To doctor in English] I told her you asked me about a translation into Karen. Yes, we have these terms in Karen.*
- [To Paw in Karen] Do you notice if your heart feels shaky when you feel nervous or stressed?*
- Paw:** *Yes, it does.*
- Interpreter:** *[Interprets verbatim]*
- MD:** *That is helpful to know. Let's check your breathing today but I would also like to consult with your psychotherapist on these symptoms to see how we can work together to improve your health.*
- Interpreter:** *[Interprets verbatim]*
- Paw:** *Okay, thank you.*
- Interpreter:** *[Interprets verbatim]*

## DISCUSSION QUESTIONS

### *Imagine you are the provider:*

- › How do you know when an interpreter is changing a word or phrase?
- › Have you noticed ways interpreters are used inappropriately or times interpreters are not used when they need to be? Are there ways to advocate for changes in these areas?

### *Imagine you are the patient:*

- › How do I feel having an interpreter? Can I trust the interpreter?
- › How do I know that the interpreter interpret everything I say?

### *Imagine you are the interpreter:*

- › How would I feel different to be the interpreter in the scenarios described at the beginning and end of this chapter?



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# Medications

## CHAPTER 8

### CASE EXAMPLE

Paw has a regularly scheduled appointment with her physician to review her medications, including medications used to treat depression, PTSD and insomnia. They are in the midst of discussing these medications here.

**MD:** Thanks for bringing all of your medication bottles today. I want to check with you to see how these medications are helping with your problems.

**Paw:** *I brought them all, but I don't think they are helping.*

**MD:** *Let's see if we can understand more about that; I think we can help.*

*I see a few things here that concern me. I see you have both your old and new prescriptions for medicine that helps with depression.*

**Paw:** *Yes, the new one wasn't the same as the old one, so I saved as many of the old ones as I could so that I could take them on days when I would just stay alone and cry.*

**MD:** *I see; I would like to talk more about how you are taking your medications.*

**Paw:** *[looks confused]*

**MD:** *I also see that your medication for sleep is all gone, though it shows that you just refilled it a little more than a week ago.*

**Paw:** *Which one is that?*

**MD:** *It is this one (points to bottle). Those pills are usually round and white.*

**Paw:** *I thought those were the ones for pain. I took two each morning and each evening.*

**MD:** *If you want to get better, you have to take these medicines just like I told you.*

**Paw:** *Yes.*

**MD:** *I am going to send prescriptions again for the medicines I want you to take. Please pick them up at your pharmacy this evening, and let's meet again in one month to check how you are taking them and how you are feeling.*

**Paw:** *I can't make it to the store, and I don't speak the language.*



**MD:** *I know your niece has helped you before. Can you check with her and have her help you?*

**Paw:** *I will do that.*

The appointment soon comes to an end, and Paw thinks to herself that she “just can’t do it right.” She is angry with herself that her memory just doesn’t work.

## Introduction

*From a Western medicine perspective, meeting with a physician, getting a prescription, picking it up from a pharmacy and following the instructions to accurately take the medication may seem straightforward. While a Westerner has been groomed to understand this routine, refugee patients often experience great confusion and misunderstanding. Health care providers may believe that these patients are being “noncompliant,” when in fact patient confusion often stems from inherent differences in cross-cultural attitudes and understanding from those rooted in a Western approach to medicine, disease and treatment. To best serve refugee patients, health care professionals need to examine dynamics of cultural knowledge, language and health literacy, as well as expectations for medications.*

*This chapter focuses on potential challenges and misunderstandings when using prescription medications with refugee patients, as well as recommendations to improve compliance and patient success with these medications. Different cultures have different beliefs about the healing process and the role of medications in improving and maintaining health. Health care providers need to explore the patient view point regarding medications, especially those chronic diseases, and be open-minded and flexible with patients.*

*Medication noncompliance or nonadherence is a problem across populations in the United States; it is estimated that approximately 50% of people take medication incorrectly; that compliance is even lower in the refugee community (Avery, 2007). According to the Center for Victims of Torture (CVT; 2005), “Compliance with medications is a common barrier to treating torture survivors and refugees in general. Many refugees have either never taken Western medications or, as with antibiotics, have taken them for only short periods of time.” (p. 58).*

*The language of compliance itself suggests the misunderstanding at the root of many medication-related problems for refugees. Compliance, defined as obeying, following orders, or acquiescing, implies a particular power dynamic, and noncompliance therefore insinuates an act of defiance or resistance. However, the reasons for not taking medication as prescribed for a refugee may be altogether different, and those reasons are discussed below.*

## Lack of Familiarity with Western Medications

Some refugees may not be familiar with the wide range of Western medications. Medication options may have been very limited in the refugee camp setting, with medications like paracetamol (acetaminophen) being the main go-to drug available for a wide array of ailments. Medications like these are taken in the moment of feeling unwell, and only until the



individual feels better. In the refugee camp, patients take medications in order to treat and cure the disease or symptom; they expect that taking a medication will fix the problem. The concept of taking a medication regularly to prevent symptoms or to manage chronic disease is foreign to many refugee patients, who feel these medicines are “ineffective” because they do not feel better after taking them, or symptoms quickly return when the medication is stopped. They may be more comfortable taking medications “as needed,” where they directly see the result of taking the medication. In addition, some refugee patients may come to the United States with assumptions there is a medicine for every problem.



## RECOMMENDATIONS

- Assess a patient’s familiarity and understanding of potential medications before prescribing; ask what kind of medicine they have taken in the past, in the refugee camp setting or prior. Offer education about the difference between an acute “as needed” medication and chronic medications that need to be taken regularly. Discuss that patients should continue to take these medications, even if initial symptoms subside or patients report they feel better now.
- Use metaphors to explain how and why to take medication as prescribed. Some examples are as follows:
  - › **Metaphor:** When you are making a recipe, you need the right amount of salt. Too much salt doesn’t make the recipe better and can actually make you feel sick.  
*Explanation: Don’t take extra pills from your prescribed medication.*
  - › **Metaphor:** Depression and worry can make a person feel like you are in a deep dark hole that you can’t get out of no matter how hard you try. Medication can help be a ladder to start to get you out of the hole.  
*Explanation: Medication can help you feel better enough to start to use other things like therapy and exercise.*

## Concerns about Psychotropic Medications

Given the current shortage of psychiatry services across the country, the responsibility for prescribing psychotropic medication increasingly falls to primary care doctors, who may feel undertrained in this area. Psychotropic medications in particular, may be foreign to refugees. Other refugees may have strong cultural and spiritual beliefs about this class of medications. There may be stigma associated with taking a psychotropic medication or a sense that taking these medications indicates one is crazy. A refugee patient may stop taking psychotropic medications when they feel better, or, alternatively, feel confused when a medication doesn’t cure them of all their sadness. Additionally, research shows that ethnically diverse populations respond differently to psychotropic medication (Chaudry et al., 2008), which often isn’t considered when prescribing medications and dosage levels.



## RECOMMENDATIONS

- Assess a patient’s understanding of psychotropic medications, including describing how the medications may improve their physical symptoms, such as sleep, fatigue, and headache. Framing the issue biologically, using basic explanations of brain functioning and the interactions of brain and body, may help overcome stigma and improve understanding.

- Carefully explain the normal progression of titrating psychotropic medications—that it may take up to four to six weeks to see improvement in symptoms, and that you may need to increase the strength (add more salt!) if the medication is helping some but not enough. Normalize the idea that pills are not a “miracle cure” and often work best when taken in conjunction with other supports (such as psychotherapy).
- Carefully explain potential side effects both with starting the medication and if it is stopped abruptly. Make sure patients know how to request and receive refills from the pharmacy before prescribing medications (see information on pharmacy-related issues on page 127).
- Start and adjust only one psychotropic medication at the time, and titrate the medication slowly with the patient in the office (avoid self-titrations). Use teach back (asking the patient to repeat instructions back to you) to ensure patients understand these medications. Keep a patient’s psychotropic medication regimen as simple as possible.
- Confirm patient understanding and regular medication use before you determine that a medicine is ineffective.
- Start with simple medication regimens to treat depression, anxiety, and PTSD; SSRIs can be very effective.
- Utilize consultation with a psychiatrist on staff if available, or determine if there is a provider in your practice with further interest or expertise in psychiatry who may also be a good resource. Consider additional psychiatric training when available as a rotation or for continuing medical education credit.

## Side Effects

Many medications have side effects that might not be easily understood by refugee patients. A patient may experience the side effects as scary or worse than the original problem. Many potential medication side effects can mimic a refugee patient’s somatic symptoms, such as dizziness, abdominal pain or headache, causing increased stress and worry. They may not understand that some initial side effects (like stomach upset in metformin) usually improve within one to two days. Conversely, patients may worry about stopping a medication when having significant side effects such as dizziness or swelling, and may continue to take medications despite these symptoms.



## RECOMMENDATIONS

- Explain the potential side effects to a patient when a new medication is prescribed. Offer advice about how to mitigate these side effects, such as drinking enough water or taking Tylenol, and explain if the side effects are temporary in nature. This will help a patient to not be surprised if they experience the effect and stop taking the medication immediately.
- Encourage patients to come talk to you if they find the side effects unmanageable and you can work together to create an alternative plan. Explain that they will not disappoint you if a medication does not work well for them.

## Memory Problems

Memory disturbance is a symptom of both depression and PTSD. A refugee patient may not take their medication as prescribed simply because they cannot remember when, how and how much to take. Refugees with complex health and mental health issues may have numerous medications, each with their own set of instructions. A quick explanation in the office about how to take a medication, even with an interpreter, may be forgotten easily by a patient. The instructions written on an after-visit summary or on the side of the pill bottle are in English, which is not useful non-English speaker, particularly if they are preliterate. Patients may not say they did not understand or could not remember instructions, as they may feel too ashamed to admit this.



## RECOMMENDATIONS

- Use teach back with refugee patients to check for understanding. This means asking a patient to repeat back to you how they will take their medication. This includes how they will remember the medication, such as by using an alarm, having a family member remind them or using a pill box.
- Ask patients to bring in all of their prescriptions and review them one by one with instructions while you look at the bottle and pill shape.
- For literate non-English speakers, write down the instructions and have them translated.
- For preliterate patients, use other reminders or memory triggers. Pill boxes are particularly helpful and can be labeled with sun and moon for morning and night. Most patients' cell phones can be set with a daily medication reminder alarm. For individuals with significant memory impairment, consider a home health nurse to come to the home to set up medications weekly, or a medication box installed in the home that automatically dispenses medication at the correct interval.

### *Confusion With Multiple Medications*

In the United States, it is not uncommon for patients with complex medical problems to be prescribed multiple medications. As refugees often present with complex physical and behavioral health symptoms, it is not surprising they are routinely prescribed and take many different medications. Commonly, each medication has its own set of instructions (e.g. take with food, take in the morning, take multiple times a day). A complex medication regimen can be challenging enough for a literate American, but for a non-English speaking refugee who may be preliterate, depressed and not accustomed to Western medication, prescribing too many medications is very challenging and can be quite risky. Patients often report they are not clear about the timing, dosing, or indication for their medications, and often end up taking their best guess.

Medication management becomes more complicated when a refugee patient is receiving medications from other prescribers outside your clinic, such as an emergency department or specialty visit. Even more confusing is when a medication has been discontinued or changed, but the pharmacy continues to dispense the old medication or a patient still has some of that medication at home. Sometimes patients' insurance coverage changes and requires them to switch from name brand to generic medications. Some patients report worrying that the new medication is not as good, won't work, or that they won't know how to take it because it is unfamiliar to them. It can be alarming when a provider learns a patient is doubling medications or taking medications prescribed years ago.



## RECOMMENDATIONS

- Ask patients to bring in all their medications to every visit, including pills, creams, inhalers, over-the-counter, and discontinued medications.
- Simplify medication regimens when possible.
- When reviewing medications, explicitly state the plan for what, how much and when to take the medications in a way that the patient will be best able to understand (see previous section on memory aids on page 67). Use reminders and visual cues on medication bottles and pill boxes
- Consider scheduling a medication when possible to avoid confusion with taking "as needed," especially if the condition is chronic.
- Remove discontinued medications, and give patients clear instructions on how to dispose of these medications. Communicate directly with the pharmacy to ensure discontinued medications are not continuing to be dispensed.
- Review medications regularly.



## DATA FOR THOUGHT

In the Healing Hearts study (Esala, Hudak, Eaton, and Vukovich, 2018), 90% of CVT clients described they were currently taking multiple medications. The quantity of medications reported by clients suggests high complexity of physical and mental health issues. For instance, clients frequently reported not knowing the names of medications prescribed by their physicians, or how or when to take their medications on a daily basis. They expressed fatigue with maintaining a medication regimen of taking multiple drugs a day, and uncertainty about how to identify and discuss side effects they experienced with their primary care providers. For example, a client explained, “I take a lot of medication. I take drugs in the morning, during the day and at night—there is so many and I forget and feel tired by it.” Integrated behavioral health care is designed to address complex physical and mental health issues in tandem, including addressing how one condition may be related to another health issue a patient is experiencing. For instance, a client described, “My pains and sickness is correlated with many things, the stress that comes up.”

## Preference for Traditional Remedies

Some refugee patients utilize traditional remedies for pain and illness, both in addition to and in lieu of Western medicines. One CVT client described treating debilitating headaches by squeezing lemon directly into her eyes to alleviate pain. Other patients have described using traditional herbs or balms for a variety of maladies. Western providers may not be familiar with the traditional approaches, many of which are based on decades of local practice and may be quite effective and yet undiscovered by Western science. Frequently patients bring or have medication sent from their home country; if there is an ingredient label it may or may not be in English. Many refugees also use local markets and or products from religious leaders to improve their health.



## RECOMMENDATIONS

Inquire about patients' use of traditional medicines, over-the-counter remedies and self-care practices, and determine if they complement or interfere with prescribed medications. Learn how the patient uses the remedy and how it helps them. If a traditional remedy is potentially harmful or interacts poorly with current prescribed medication, voice your concern and offer education to the patient. If it is not harmful, be careful to not dismiss the remedy or necessarily discourage its use. Many patients get good support and relief from these treatments and it may be a helpful adjunct to their care plan.

## Mistrust

Some refugee patients may not trust Western medicine and immunizations, or may hear messages that certain immunizations cause autism or other diseases. Others may not trust the health care system, as with a patient who told her social worker that she would never get an operation in a Western hospital because she had heard doctors experiment on refugee patients in the United States. The same concerns may hold true with prescription medications as well.



## RECOMMENDATIONS

Provider–client trust is at the core of uncovering a patient’s potential concerns. If you don’t have a patient’s trust, they likely will not tell you of these kinds of fears; they simply won’t take the medication. You can open the door to this conversation by letting the patient know that you have heard about community worries related to Western medications and want to talk with the patient openly about any worries they have that might make it hard to take the medications.

### *Problems Using the Pharmacy*

Obtaining medications from a pharmacy is often a completely foreign experience for a refugee client. They may not know where their nearest pharmacy is located. They may not have transportation to get to the pharmacy. If they are able to make it to the pharmacy, it is likely the employees will be exclusively English-speaking. Patients may not understand co-pays and may not be able to afford them. Even if a refugee patient manages to handle the financial transaction, they may not understand important oral or written instructions from the pharmacist. Patients and their helpers are often unable to read medication labels and may rely on medication shape, size and color to identify the appropriate medication. This can be problematic as different medications may look similar to one another and have very different functions and directions. Additionally, when a pharmacy changes the brand of medication, the prescription may have a new color or shape. For ongoing medications, refugee patients may not understand refills, may assume that once a bottle of medication is finished they are done with that medication. They may think they have to return to their physician to get another bottle, and will discontinue medications until they can be seen.



## RECOMMENDATIONS

- Before prescribing a medication, proactively ask your patient if they have filled a prescription before and how they navigate the process. If a patient is confused, offer education: where to go, who to talk to, what potential costs such as co-pays may exist.
- If patients are non-English speakers, ask if someone who speaks English can go along to help or provide a note, message or instructions they can share with the pharmacist indicating the patient’s name and which medication they are there to pick up.
- Get to know the local pharmacies that your patients commonly use. Do those pharmacies have employees that share language or country of origin with your patient? Can they use an interpreter language line to communicate important information with non-English speaking clients? For patients without access to transportation, can their medication be delivered? How can this be set up?
- Explain the refill process to patients, and the appropriate time and process to request refills. If you are changing a dosage or brand name of a medication, inform your patient that the color, size, shape of the pill might change. Call the pharmacy when medications are discontinued so they do not continue to fill those medications for the patient unknowingly.

### *Lack of Communication With Providers*

Given the many barriers patients experience in obtaining, understanding, and taking their medications, many refugee patients may not safely or appropriately take their medication and may not know or feel comfortable sharing this with the prescribing provider. Refugee patients may be embarrassed to admit they didn’t understand the instructions, may not want to insult a doctor if they determined a medication is not helpful or have stopped taking it, or may not know they

are not taking medication correctly. Patients may not be able to access medication because their insurance has lapsed. Doctors may not have the time they need in an appointment to figure this all out. Refugee patients may instead share this information with their therapist or social worker, who can help clarify confusion and facilitate understanding between the patient and the prescribing provider.



## RECOMMENDATIONS

- Team members need to work together to ensure a patient will be as successful as possible with medication. Therapists have more time with patients, with weekly 45 to 60 minute appointments. They can improve patient success with medications by assessing adherence and potential side effects.
- Patients may stop medications with lapses in insurance coverage. Social workers, insurance guides and care coordinators can play an important role in assisting patients to troubleshoot insurance lapses and the subsequent impact this may have on access to medication. Are there samples you can provide during an insurance lapse? Do you have pharmacy gift cards you can give patients that can cover the cost of a medication (or the co-pay if a patient is unable to pay)? Is there a generic medication that might be less expensive or covered by insurance? Are there other providers working with the patient who can help with medication management and need to be part of the discussion, such as a home nurse, on-site pharmacist or personal care assistant?

## *Diet Concerns Related to Medication*

In the camps, many refugees experienced malnutrition, as access to food is limited and rations are heavy on a starchy staples such as rice. Families may have grown their own fruits and vegetable and raised some animals, but this is often limited (Wagner et al., 2015). When refugees come to the United States, they are suddenly exposed to (and often can only afford) large amounts of inexpensive, highly processed foods, high in carbohydrates, salt and sugar. This change in diet, amongst other factors like chronic stress, puts some refugees at high risk for developing chronic medical conditions such as diabetes and high blood pressure. Lack of education about healthy diet and prevalence of low cost processed foods likely contributes to these diseases.

Religious practices and cultural beliefs may also impact a patient's ability to follow a recommended diet or take medications. For example, many gelatin capsules are made with pork, a food not consumed by many Muslims refugee patients. Some Karen women believe that drinking too much water will cause them to gain weight. Insulin, an important medication in diabetes, is often taken with meals, and many Southeast Asian patients traditionally eat two meals per day, not three. Muslim patients fast during Ramadan and do not eat regular meals during the day. Also, patients of many faiths may fast at times through the year and refrain from taking medication (particularly those for which they need to take with food) during this religious observance. These patients need an adapted medication regimen that aligns with their meal schedule.



## RECOMMENDATIONS

- Inquire about common dietary routines of a patient's home culture and sensitively address how these practices impact health. Ask specific questions about what makes up a patient's diet. Consider these practices when prescribing.
- Take religious considerations into the picture and find other options if there are barriers. For example, is it possible to prescribe a non-gelatin based pill? Are there vegetarian version of the medication?
- Learn from a fasting patient if their faith practice provides an exemption for needed medications, and what might need to happen for the patient to make use of such an exemption.
- Consider recommending diet and physical activity to treat disease alongside or in place of medications. Often times educating patients on healthy choices can be more effective than medications.

# MEDICATIONS BY CLASS: PITFALLS AND RECOMMENDATIONS

## *Antibiotics*

### Common Pitfalls:

- Patients may just take antibiotics until they feel better and save the remainder for the next time they feel bad.
- Patients may bring antibiotics from their home country or buy them at local markets, as this is common in other countries (usually amoxicillin).
- Patients may stop taking an antibiotic due to stomach upset or diarrhea.



### RECOMMENDATIONS

- Always discuss frequency and duration of antibiotics with patients. Educate patients to take all of their antibiotics, even if they are feeling better.
- Ask patients if they are taking medications such as amoxicillin for infection. Educate patients that it is important to take the right antibiotic or they might become sicker.
- Encourage patients to take antibiotics with food or yogurt. Discuss that loose stools are common with all antibiotics, but that they should still finish the medication and symptoms will improve.

## *Pain Medications*

### Common Pitfalls:

- Many refugee patients do not understand or well utilize common over-the-counter medications. They may not be aware of other medications besides Tylenol (paracetamol). Often, they are afraid to take Tylenol and Ibuprofen together, or how to alternate doses.
- Many refugee patients are not familiar with taking medication “as needed” and are often reluctant to take a medication more than once per day. Most are not familiar with the idea of taking a medicine, waiting four to six hours, and taking it again if pain persists.
- Given the acute lens often brought when diagnosing client pain, medications that could address chronic pain or more extreme pain are often not prescribed.
- Gabapentin has been used successfully for a number of patients with chronic pain; however, its frequent administration schedule and potential side effects can be discouraging and challenging for patients, especially when not explained in detail. PO administration plan and side effects are not often relayed in detail.



### RECOMMENDATIONS

- Pain medications may be more effective if given on a schedule instead of as needed, so that a patient can stay head of the pain. It also simplifies the schedule and routine for patients to follow.
- Many patients note that poor sleep that affects pain and pain can cause poor sleep. Using sedating pain medications such as gabapentin or tricyclic antidepressants before bed can effectively improve both pain and sleep.
- Many patients report good pain relief with topical products, both ice, heat and medicated creams such as capsaicin or lidocaine. These may be easier for patients to use and can be an effective “as needed” medication.



## Antidepressant Medications

### Common Pitfalls:

- Most antidepressant administration and titration schedules are confusing and frequently misunderstood by patients.
- Taking a medication for an extended period of time for a chronic condition is often quite unfamiliar.
- Side effects are common at the outset of starting an antidepressant medication and can be concerning for patients, especially if not preemptively explained to patients in detail.
- Antidepressants typically take four to six weeks to demonstrate an effect. A refugee patient is apt to discontinue these medications prior to follow-up, due to seeing no apparent benefit and early but self-limited side effects.
- Refugees may not be familiar with SSRI discontinuation and withdrawal syndrome, and abruptly stopping these medications can lead to suffering and confusion about what is causing these problems.



### RECOMMENDATIONS

- Carefully explain the purpose, administration schedule and potential early side effects with patients prior to starting an antidepressant.
- Stress the importance of taking the medication regularly and explain potential side effects if the medication is stopped suddenly. Encourage patients to come in and talk to you if they want to stop the medication so it can be done safely, without side effects. Schedule sedating SSRIs and tricyclic antidepressants to be taken at night to improve sleep and daytime function. Assess patients for daytime sleepiness and adjust as needed.
- Medication reminders, including phone alarms, help from family members (or PCAs and home health nurses), use of graphics, and use of pill boxes can assist in patients' understanding and taking an antidepressant regularly.
- Make sure to screen for symptoms of mania, and avoid antidepressants in patients with symptoms concerning for mania.

## Sleep Medications

### Common Pitfalls:

- Many refugee patients work uncommon hours, with late night, overnight, or early morning shift work. Many travel long distances to get to work, where excessive daytime sleepiness can be dangerous.
- Taking a sleep medication can be problematic for a refugee patient with young children if they feel compelled to attend to them during the night, or if there is an expectation of early morning chores, such as cooking, that need to be completed without feeling too drowsy.
- Some refugee patients may take as many of these medications as needed to fall asleep, risking overdose.
- Medications like prazosin frequently used to treat PTSD nightmares also lead to dizziness, lightheadedness and low blood pressure, which can cause falls.



## RECOMMENDATIONS

- Collect a complete sleep history, as knowledge about appropriate sleep schedule and sleep hygiene can be a new concept to many refugee patients.
- Education about sleep hygiene practices can go a long way and may be especially helpful to address when treating sleep concerns.
- Carefully describe sleep medications, what to expect and potential side effects before prescribing. When prescribing prazosin, closely assess and monitor a patient's blood pressure. Assess for symptoms of hypotension such as dizziness, lightheadedness and clamminess. Encourage patients to get up slowly when awaking during the night, and sit at the side of the bed before getting up.

## *Diabetes Medications*

### Common Pitfalls:

- Chronic diseases diagnoses such as diabetes, are not well understood by refugee patients. Frequently, patients are confused because despite taking their medications in the short term, the disease does not go away.
- Patients may not understand the importance of regular medication administration.
- Culture, religion and meal timing frequently differs from the “three square meals a day” model of Western patients. Many refugee patients do not eat breakfast, which can cause dangerously low blood sugars.
- Many patients have fears and phobias about needles due to past experiences, making it challenging for them to take insulin or check their blood sugars.
- Patients may have limited education about diet and exercise and may have limited access to fresh, healthy food or safe places for physical activity, as they live in low-income areas.



## RECOMMENDATIONS

- Ask patients about how they eat their meals—when, with whom, how often, what type of foods. Discussing food is also a great way to connect with people.
- Discuss diabetes as a chronic disease process, and explain how diet, exercise, weight loss and medications all work together to keep them healthy and feeling good. Education about blood sugar, glycemic index and behavior modifications that can be extremely effective. Often, patients have reported that the solution they have been told about is to simply “eat less rice.” Design simple behavioral change interventions in partnership with the patient.
- Counsel patients on ways to treat low blood sugars. Consider prescribing glucose tabs or discuss having hard candy or juice available.
- Give patients a log book to record their blood sugars. Pictures such as sun and moon for night and day work well for this.
- Keep diabetes medication regimens as simple as possible. Try to use extended release versions of medications to decrease risks of low sugars and other side effects.
- Make slow, stepwise changes in diabetes medications together with the patient in the office. Schedule frequent follow-up visits, and review with patient techniques used to give insulin. Ask about areas of pain or bruising at administration sites.

## Blood Pressure Medications

### Common Pitfalls:

- Patients' high blood pressure might be associated with PTSD and trauma symptoms. Elevated blood pressure may indicate worsening symptoms, or increased stress, worry and anxiety.
- Elevated blood pressure can also reflect uncontrolled chronic pain, which patients may not bring up themselves during the visit.
- Patients often do not feel "ill" when their blood pressure is high, and therefore may not understand why taking a blood pressure medication is important.
- Gouty flares, a common disease in East Asian patients, are a common side effect of the blood pressure medication, hydrochlorothiazide, which may lead to discontinuation of medications.



### RECOMMENDATIONS

- Always check that patients are actually checking and taking their medications before increasing the dose or adding a new medication.
- Discuss how body and mind are connected; that blood pressure is affected by mood, stress, sleep and pain. Share how participating in relaxation activities and therapy may have a positive impact on blood pressure.
- Educate patients on potential side effects of blood pressure medications.
- Consider using beta-blocker medications, specifically propranolol to treat blood pressure in patients who experience anxiety with palpitations or rapid heart rate.
- Blood pressure medications are sometimes offered as needed to help manage panic symptoms and extended psychoeducation about this use is beneficial.
- Consider using prazosin to treat PTSD, nightmares or increased hyper-responsiveness in patients who also have high blood pressure.
- Consider using combination blood pressure medications to help simplify a patient's medication once their blood pressure is stable.

## High Cholesterol Medications

### Common Pitfalls:

- Similar to blood pressure medications, patients may not understand the purpose of the medication, as they do not "feel better" when they are taking their blood pressure medication.
- Many refugees have very high cholesterol levels, which require high doses atorvastatin. These pills are very big and can be challenging for patients to swallow, making it challenging to take the medication.
- There are some risks of muscle problems with higher dosage used, and this experience can be confused with other sources of chronic pain and muscle tension.





## RECOMMENDATIONS

- Discuss the purpose, timing and potential side effects of statin medications with patients before starting medications. The risk of muscle pain and next steps if they develop this pain needs to be carefully addressed.
- Consider the long-term benefits of cholesterol medications in elderly refugee patients and consider discontinuing in the elderly.
- Review lab testing to confirm whether or not patients are taking the medications, and if necessary explore reasons for discontinuation, including large pill size.

## *Stomach Medications*

### Common Pitfalls:

- Sometimes stomach or gas medications are thought to treat “heavy heart” (which may actually be depression), and if these medicines alone are not helpful in improving symptoms, patient may lose hope for any treatment being helpful.
- The “as needed” administration of these medications can be confusing, and often patients will resist taking these medications until problems are overwhelming.
- Patients may feel uncomfortable talking about their bowels, and constipation is a common problem as refugees adjust to a Western diet.



## RECOMMENDATIONS

- Discuss diet and lifestyle changes as well as prescribing medications. Elevating the head of the bed, along with decreasing caffeine, alcohol and certain foods at night, can have a significant impact on symptoms.
- Always screen for depression, anxiety and alcohol use in patients with stomach pain.
- Ask about constipation, as it is a common side effect of many medications, and many patients will not feel comfortable bringing it up on their own.
- If a patient has significant stomach symptoms, consider using a scheduled medication, such as an H2 blocker like famotidine to ensure appropriate treatment of stomach symptoms.
- Carefully discuss how to use as-needed stomach medication before prescribing. TUMs has a distinct chalky taste and flavor which is memorable for patients. This tends to work well as an as-needed medication for occasional symptoms and can be added to a scheduled medication.



## SUMMARY OF RECOMMENDATIONS

Assess patient familiarity with medications, and use metaphors when appropriate to describe why and how to take them.

- Explain psychotropic medications carefully.
- Explain potential side effects of medications and ask patients to tell you about side effects before stopping a medication.
- Use a teach back method (where patients repeat information back to you) for patients with memory impairment or when multiple medications are prescribed; use tools to help with memory that match literacy and need (from a pill box to a box that dispenses medication automatically).
- For refugee patients on multiple medications, ask patients to bring their medications to each visit. Discard old prescriptions. Work with the pharmacy to ensure old prescriptions not being filled.
- Ask about traditional remedies. Don't dismiss them if they are not harmful. If contraindicated or harmful, inform patients.
- Build trust and shared understanding. Refugees might not trust Western medications.
- Ask patients if they have used a pharmacy before; if not explain how they work, and inquire if there is someone they know who can help as needed. Explain how refills work.
- Inquire about diet and religious considerations when prescribing medications.
- Review above chart for recommendations by medication class.

### CASE EXAMPLE: RESOLUTION

Paw meets with her doctor at her next scheduled appointment and they return to their conversation about medications.

**MD:** *Paw, nice to see you again and thank you for bringing in all your medications.*

**Paw:** *My niece helped me get the new ones but I am really confused.*

**MD:** *That makes sense. There are a lot of medications here and each one has different instructions. Let's look at them together one by one. I see here that you still are getting two different medicines for depression and they do the same thing. So you should just take one. Is it okay if I take away the old one and discard it?*

**Paw:** *Yes please do. I can't tell which is which.*

**MD:** *And I am going to call the pharmacy right now, because I asked them to stop giving you this one, but it doesn't seem like that has happened. [Makes call, confirms pharmacy will no longer dispense that medication. Places a big X on the bottle that was discontinued.]*

**Paw:** *I can't remember which one of these medications is for sleep and which is for pain? I don't know what the sides of these bottles say.*

- MD:** *Okay. Let's think about this. How about if I draw a picture of the moon on the one for sleep. Would that help you know that is what this medication is for?*
- Paw:** *Yes, that would help. How often do I take that one? And how often on the pain one?*
- MD:** *So those two are both for you to take when you need them. You don't have to take them every day, only when you feel pain or at night when you can't sleep. But you can only take a certain amount in a day if you need it, you don't want to take too much.*
- Paw:** *How will I know how much?*
- MD:** *Remind me, do you read in Karen?*
- Paw:** *I don't. With the war I didn't go to school since I was seven.*
- MD:** *Would it be helpful if I have a home health nurse come to your house each week and help you set up these medications until you feel like you have learned how to take them?*
- Paw:** *Yes. I am still confused and I need help.*
- MD:** *Okay, I will do that. Bring your medications again next visit and we can go through them again and we can talk about what you have learned from the nurse and what still is confusing. One important thing is that this depression medication is different than the sleep or pain medications in that it is important to take it every day at the same time. Even on days when you don't feel so bad. Is it okay to bring your niece in now so I can tell her and perhaps she can help remind you? When the nurse comes, she can set up a system to help you remember too.*
- Paw:** *Yes, thank you that would help. My niece has a good memory and she helps me a lot.*

## DISCUSSION QUESTIONS

*Consider your current role as a provider:*

- › What do you see as within your role as a provider compared to what is outside your role regarding medications?
- › In a situation like the case with Paw, how would you differentiate roles between the nurse, primary care physician, social worker and psychotherapist regarding medications? What consultation would be beneficial with this arrangement?
- › Do you see anything that could have been done earlier in Paw's case to improve her ability to manage her medications?

*Imagine you are in Paw's position as a patient:*

- › How do you feel about your plan for medications? Are there elements that remain confusing?
- › What would increase your hope that medications could improve your health at this point?



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# Social Support and Community-Level Interventions

## CHAPTER 9

### CASE EXAMPLE

Paw meets with her social worker, Mai.

**SW:** *Paw, how have you been this week?*

**Paw:** *I am feeling a little better. I think I understand my medication and am taking it right. This is making me feel good. But I am feeling very bored.*

**SW:** *Tell me more about what you did during the week?*

**Paw:** *I stayed at home. I sometimes cooked.*

**SW:** *Did you go out of the house for any activities? Did you talk to any friends?*

**Paw:** *No. I stopped going to church because I think they all know I am sick and think I am crazy. I miss the church but feel like people are staring at me. I wish my daughter was here. She would help me feel brave.*

**SW:** *Do you mean your daughter who is still in Thailand?*

**Paw:** Yes.

**SW:** *Remind me why she did not come to the United States when you came as a family?*

**Paw:** *At the time, she did not want to leave Thailand. She was about to get married and did not want to come. She wants to come now but I think it is impossible.*

**SW:** *Would it be helpful if we called an immigration agency to ask some questions to find out if your daughter cannot come or if there might be some path to her coming?*

**Paw:** Yes, that would be helpful as I am not sure.

**SW:** *Do you get to communicate with her?*

**Paw:** *She sometimes sends messages to my other daughter on the phone but I do not know how to write back.*

**SW:** *So she has a phone?*

**Paw:** *She does but it is not strong enough for the kind of call where I can see her. I have seen other people doing that.*



- SW:** *I may be able to help with a calling card. You can use it to at least call her and talk over the phone.*
- Paw:** *That would be so nice.*
- SW:** *You said you don't feel comfortable going to church right now. Do you feel like you have other ways to be around people in addition to your family? Do you have friends here?*
- Paw:** *No. There are a few Karen women in the apartment building where I live and they say hi to me and have invited me to eat, but I say no. I don't know them; I did not know them in Burma. I think they also might think I am crazy. They do seem nice though.*
- SW:** *You have said a couple times you worry people will think you are crazy. Can you tell me more about that?*
- Paw:** *My first husband in Burma always told me I was crazy. Even before the war. He would tell me no one would ever like me because I am crazy and dumb. He was not a nice man. He used to hit me a lot. I am glad I am away from him. My husband now is not this way.*
- SW:** *That sounds terrible. I imagine you felt very bad during this time. And I wonder if even though he is not with you anymore, if some of the things he said to you are still in your head.*
- Paw:** *Yes they are. I think he is wrong, but sometimes I am not sure.*
- SW:** *Have you talked with the therapist about any of this?*
- Paw:** *I have not.*
- SW:** *I really encourage you to do so. Maybe she could help you change some of those messages out in your head. This could help you to feel freer to try church and maybe get to know the women in your apartment that seem nice. All three of us could work together on that, what do you think?*
- Paw:** *I think it is a good idea. I don't want that bad man in my mind anymore.*

## Introduction

Unlike trauma caused by nature or by an accident (such as a hurricane, flooding or an automobile collision), refugee trauma is trauma of human design. As such, it is initially protective for individuals to fear or not trust other human beings, as the source of their trauma. However, since humans are social beings, isolating oneself from others can prevent healing and maintain or worsen mental health symptoms over time. Communities can be natural sources of strength and support, and can be looked to for health and healing when working with refugee patients. Health care providers need to assess and support social interaction and connection for refugee survivors at a pace an individual refugee can tolerate. This chapter focuses on social support from family, friends and community.

In the example above, Paw describes several challenges she currently faces when it comes to social support and connection with family, friends and community. Many of the fears and hesitations she raises are



*connected to her past war trauma experiences, as well as other traumatic events (such as a former abusive husband). It appears that she would like to be more socially active and engaged. She also faces ambiguous grief about the separation from her daughter with whom she is doubtful she can reunite.*

## Assessing and Intervening With Social Connections

Engaging with the community system can feel like a complicated process when working with an individual patient. However, family, friends and the broader community can be natural sources of support and resilience. Families often support patients in making it to appointments and keeping track of treatment recommendations, such as medications and referrals. Community supports such as churches often provide supports to new arrivals, such as clothing, as well as spiritual support that can have a positive impact on health and wellness.

In the scenario above, the primary care clinic employs a social worker who is trained and has time to help patients with social reconnection. In some clinics, there is no social worker on site. In others there may be one or two social workers whose time is predominately focused on basic needs care (like helping patients access food support, insurance, clothing, etc.). In these scenarios, assessing for social reconnection may fall to other providers, such as a psychotherapist. Or, these needs may go unassessed and untreated. CVT has found it ideal to have both a social worker and a psychotherapist on staff at primary care clinics to divide work on the many needs of the patient. The social worker helps not only with pressing basic needs, but also with the essential need that human beings have to feel and be connected to others. CVT social workers and psychotherapists also work closely together and share treatment plans and goals to not duplicate services. An added benefit is that the two professionals can debrief and provide support to each other as a means of mitigating secondary trauma.



### RECOMMENDATIONS

If your clinic works with a significant number of newly arriving refugees and you do not have a social worker to address basic needs and social connection, it is highly recommended the clinic advocate for this. Otherwise, it will be inevitable that these issues—which are often very complicated and time consuming—will not only take time from other medical appointments, but also will potentially stall or prevent improvement in an individual's health. If hiring social work staff is impossible, it is recommended that a clinic develop a close relationship with a local social service agency working with refugees.



## SOCIAL CONNECTION: THE FAMILY

### *Family Separation*

Many refugees are resettled as a family unit—the definition of family unit here being very U.S.-bound, consisting of mother, father and biological minor children. This definition is much narrower than the definition of family for many refugee groups. Aunts, uncles, grandparents, cousins, nieces and nephews may make up the fabric of very close family. Children may have been informally adopted when parents died in war or were unable to care for children. Close friends may be considered, and called, family members. None of these individuals may have been resettled with a refugee patient’s family. And, for one reason or another, sometimes even the nuclear family members are not able to resettle together. It is important to ask

patients about their family makeup (using their definition of family) and who is here with them in the United States. It is also important to ask if family members remain at home or in a refugee camp and to better understand those circumstances. These are often difficult and painful conversations.

Asylum seekers likely (though not all of the time) have fled their country without their family members. Often they are only able to get themselves out for a number of safety and financial reasons. Asylum seekers often experience extreme guilt, worry and fear about family separation, especially if their family is in danger or financially reliant on the asylum seeker. It is important to assess family separation for the asylum seeker.



## RECOMMENDATIONS

While it may feel impossible to provide any kind of intervention for family members who are not in the United States, there are often things you can do to help. In Paw's example above, she is doubtful her adult daughter can come to the United States, but she is not certain and does not know the immigration laws well. A call to an immigration lawyer to consult or to set up a meeting with the patient can help clarify the issue. Even if reunification is impossible (and often there are possibilities once citizenship has been obtained by the patient, albeit this can take many years), patients can be helped to have a definitive answer. In some cases, you may be able to help facilitate communication between patients and separated family members, via a calling card or internet connection—particularly as technology now reaches more remote areas of the world. In the case of a separated asylum seeker, you may be able to advocate with an attorney or legislator to request an expedited case. Familiarize yourself with legal immigration services in your area and establish relationships with those providers, who are often excellent sources of information.

## Resettled Family

Refugee families who receive the decision to be resettled together in the United States experience great joy and relief. For families that are separated and reunited after obtaining asylum, the reunification at the airport is often an incredibly powerful and emotional experience. But coming to the United States or being reunited after a separation is often not a neat fairy-tale ending. A lot of work, adjustment and accommodation must happen once a family has arrived in the United States or has been reunited.

The Center for Victims of Torture (2005) describes some of the potential dynamics for resettled and reunited families:

*Once a family is reunited, there is a honeymoon period. Family members are overjoyed with the sheer miracle of reunification and their survival as a family against incredible odds. Families that shared traumatic experiences and relied on one another for survival show particularly close bonds and continue to do everything together.*

*As the family's resettlement proceeds, the effects of torture trauma begin to surface in a complex manner. Such effects interact with the stresses of cultural adjustment, loss of economic and/or social status, events back home (e.g., war, destruction of property, deaths and torture of friends or extended family), and other ongoing trauma the family may be experiencing in their new community (such as racism, neighborhood violence, etc.).*

*Cultural differences may create conflict and upheaval for families coming from different cultural contexts. For example, compared to more traditional societies, culture in the United States places relatively greater emphasis on individualism, competition, mobility and fast pace, materialism, youth culture, technological innovation and change, and the nuclear*



*family as the basic family unit. Resolving conflicts between traditional and newer values is difficult without trauma. When one or more family members is coping with effects of torture, these issues become even more daunting. (p.15)*

With these potential dynamics in place, common effects or outcomes of torture, war trauma and displacement on a refugee family include the following:

- Loss of cultural and social supports due to fear, distrust, sense of betrayal, etc.
- Social withdrawal or isolation.
- Marital and/or intergenerational conflict.
- Parental functioning affected by parents' symptoms (e.g., parents are often less emotionally attuned and attentive to children than they otherwise would be, due to being exhausted and distracted by symptoms of depression and post-traumatic stress disorder).
- Low tolerance for negative emotions (e.g., a parent can't stand to hear a baby cry because it reminds the survivor of memories of other prisoners' screams).
- Silence within the family regarding the torture and other trauma (i.e., what happened to whom and why), sometimes leading to confusion, misunderstanding, multiple versions of what happened and unaddressed blame, shame, anger, disappointment and sadness.
- Parent-child role reversal (parents experience disempowerment due to both trauma-related symptoms and loss of their traditional role in the new culture; children prematurely assume adult roles due to more rapid language acquisition and acculturation).
- Pressure on children to be immune to effects of the family's ordeals and to succeed (often to make up for what the family lost). (Center for Victims of Torture, 2005 p.15)

## RECOMMENDATIONS

Given all these complicated dynamics that can occur simultaneously, how do you as provider intervene? As with most aspects of care, the first step is to become aware of these dynamics. Some of them may be more immediately apparent, either because they are visible (a parent asks their child to interpret for your session when the professional interpreter cancels, or a child brings in their parents health insurance paperwork asking you to check that the child filled it out correctly, or your patient tells you her husband has started drinking heavily and verbally berating her since he was laid off from work). Others may not be visible nor readily observable (a patient does not tell you she is being physically abused by her husband for fear of the information leaking to the community and becoming ostracized, or a mother who isn't aware herself she regularly dissociates throughout the day while caring for her children). Some of these dynamics are likely to emerge over time and with trust. Others you may never be fully aware of.

Once you are aware, interventions can include providing education and support to patients. Let patients know that these dynamics, like the ones listed above, are common and predictable responses to adjusting to life in a new country after war and torture. Find sources of support depending on the specific familial issue.

For domestic violence, offer referrals to agencies that will provide cross-cultural support. If you are referring to or involving community members, be sure you have a sense of the role they might play with the patient and the community in terms of confidentiality and respecting the rights of the patient. (For example, CVT providers have had experiences where a taxi driver from the patient's community disclosed her whereabouts to her abusive husband, and another situation where an interpreter had previously known the patient in a different role and had encouraged her to return to their abusive husband and make peace.) For parenting support, look to local ECFE programs for young children and parents who need support, and reach out to school social workers for older children. Look for parenting groups specifically for refugee families in your community that can help share norms and laws in the United States related to what is considered abuse. Consider referrals to family therapy. Of course, specific interventions will depend on the specific problem presented and on your available community resources.

## Family Presence in Appointments

What should providers do when they have scheduled an individual session with a patient and she shows up with family members? Invite them into the session? Ask them to stay outside? This situation is one in which providers have to make a split second decision without always being able to weigh all the consequences.

### RECOMMENDATIONS

The answer is not a simple one: It depends. CVT providers have been in situations where it has been incredibly helpful to have an adult acculturated child of a depressed and often confused patient come into session and explain to us which medications have been prescribed, who exactly are all the patient's providers, what are the details of the lease that was just signed on an apartment, etc. And there have been other occasions when adult children express concerns in session, with their mother present and silent, that she is not capable of caring for herself or making decisions—only to find that same woman talkative and insightful about her problems when the daughter is not present.

Also consider the impact of having small children in the room in session. It is not uncommon that mothers of young children especially need to bring their children with them for appointments. Unless you have a dedicated person or service at your clinic to care for children during a parent's appointment, you may have no choice but to have the child or children in the office with you. In this situation consider that how and what you talk about might affect the child or children. You might have to modify what you talk about (particularly traumatic material) depending on who is in the room, and perhaps focus on brainstorming ways for the patient to find care for her children so you can have time and space to speak freely when needed.

These decisions involve many considerations, not the least is which to consider your own norms and culture when making them. Even the idea of treatment at the level of individual may be a foreign concept to some refugees, and it is important to adjust treatment needs and approaches centered on Western notions of the individual. In the end, the best guidance on involving family members may be a both/and recommendation. That is, it is both helpful for family members to be involved—to share information, play a role in supporting the treatment of their loved one if appropriate and to provide opportunity to observe familial dynamics—and to offer space and time individuals to be able to share what they may not feel comfortable sharing in front of other family members and to observe the individual's capacities without helpers present.

### EXAMPLE

A refugee from an African country encountered severe war trauma, including witnessing human rights atrocities. He was so severely impacted that he did not walk or speak following the traumatic events. In treatment, the providers engaged the patient's family member in session. Individual psychotherapy sessions focused on the individual trauma survivor, and 24-hour care was provided at home by family members. In this case, bringing a family member into session was instrumental; the therapist was able to provide psychoeducation on trauma to those in the family system who were caring for the survivor. The therapist also modeled therapeutic activities, such as coping and social rehabilitation skills, that the family members could encourage and practice at home after session. In case management sessions, the family member was instrumental in providing needed information to obtain needed benefits and to maintain in-home services. The family member was also able to provide the case manager with details about the patient's functioning in

the home to engage additional services that were helpful for the family, such as respite care. Family members were also able to confirm medication compliance and detail the side effects of new medications, which allowed the providers to coordinate with primary care services to ensure wrap-around care. Finally, the family member was able to provide a report on treatment goals to the providers, such as progress in walking and speaking, which were relevant to measuring progress and shaping treatment interventions.

### EXAMPLE

A refugee from Southeast Asia saw a therapist and case manager for individual services. She had a complex home life with many social stressors, including an abusive relationship and financial hardship. The therapist focused on recovering from intimate partner violence and utilizing coping strategies to manage worry and depression when managing finances, basic needs and county benefits. The therapist engaged the patient's daughter in session once every other month. This decision was made so the family could share current social stressors and get updates on the patient's progress in treatment. Because many of the issues impacting the patient's mental health were related to the social environment, this allowed the therapist to manage those issues directly with the patient. It also allowed for an opportunity for the therapist to model communication and problem-solving skills with the family member that the patient had been working on to mitigate stress and emotional reactions.

### EXAMPLE

A refugee from the Middle East fled her country after her family was threatened by a militia and her husband and son were killed. She is 55 years old and lives with her remaining son and daughter-in-law. Her diagnoses are diabetes, high blood pressure, PTSD and major depressive disorder. At her first case management appointment, the patient's son requested to come to the session to provide information about her. He told the case manager that she is "crazy" and that she cannot leave the house to work or learn English. He said that she cannot make good decisions and that he and his wife cannot leave her alone. He requested to come to each appointment with her. The case manager asked her about this, and she replied, "Whatever you think." The case manager suggested that she and the patient meet alone for the next session to see how it goes. At that session, the patient told the case manager that, while she is sad about the past and overwhelmed by all the new things in the United States, she wants to go to English class so that she can eventually work. She reported that she does not want public benefits because she would feel ashamed since she wants to work. She stated that she and her son disagree about using public benefits and about her leaving the home for activities. She said that it is helpful to have time to talk about her struggles without family around. The case manager and the patient planned to meet individually and only invite her son in if it is necessary. She and the case manager also agreed to work with her therapist to find ways for her to talk with her son about her goals without disrupting her relationships at home.

## Social Connection: Friends

Refugees living in exile likely have experienced multiple severed friendships. Friends may have been killed or imprisoned during war or torture. Friends may have been lost when soldiers or rebels invaded villages and communities had to flee. Friends may have been left behind at refugee camps during the resettlement process.

And now in exile, new friendships may be actively avoided or passively neglected. Torture survivors, in particular may actively avoid connecting with new people post-torture. The Center for Victims of Torture (2005) offers insight into this phenomenon:

*Reports among torture survivors include experiences of betrayal (being turned in to authorities) by friends, colleagues, or even relatives. Feelings of distrust permeate various levels of a repressed society, which pave the way for widespread distrust of all people and institutions. Chronic fear becomes a way of life and paralyzes the community as a whole.*

*Lifelong neighbors, friends, and sometimes relatives, lose their trust in one another as group is set against group. Former friends and confidants become bitter rivals and enemies. In a very short amount of time, entire communities become polarized and fragmented. Fear, distrust, loss, and traumatic experiences force a constriction of families' social networks, resulting in social isolation. (p. 13)*

Refugee patients may not trust others and may go out of their way to avoid eye contact or initiate conversation with someone they do not know. Many refugee patients express initial apprehension about joining CVT therapy groups offered within a safe and structured environment. This fear extends (and in some cases is even stronger) with members of their own community:

*Some people may be from the persecuted group in their home country, while others may be from the group that perpetrated the torture. Torture survivors often live with the fear of encountering their torturers or unknowingly befriending current informants in their new communities. This fear may be realistic; it is common for the "eyes and ears" of a terror-based regime to extend into communities of exile. (Center for Victims of Torture, 2005, p. 14).*

Additionally, patients often report worries that connecting with new friends will require them to disclose traumatic events from their past that brought them to the United States. In the course of meeting new people, many patients report being asked about what happened to them in the past that made them flee their home, where their families are and other questions that bring up traumatic memories. For this reason, some patients hesitate to build relationships with others.

## RECOMMENDATIONS

- When meeting a new patient, assess for social relationships outside the family. Ask about relationships prior to coming to the United States with awareness that there may be grief associated with separation or loss of those friends. If a patient has few or no friends, assess their level of interest and ability to connect with others. Some patients, like Paw in the above example, may feel afraid to connect with friends for a variety of reasons connected to past traumatic experiences. It is important to hear and understand those fears. Getting to know and trust you and other providers may be the critical first step for patients to eventually reach out to others.
- Familiarize yourself with resources either within your clinic or outside that may be safe forays for patients to get to know other people. Do you or can you offer a group within your clinic that may be a safe and natural way for individuals who may have things in common to get to know each other (e.g., a new arrivals group, a mothers group etc.)? If you do not have resources to create a group, what groups exist in the community? Often refugee



assistance agencies offer groups on any number of topics. Knowing what your patient is interested in can help you to find the right fit for social activities. Many communities have day centers or programs for elders to socialize during the day. Some communities have gatherings based around common hobbies such as crafts, sports, cooking or being in nature. Once you know your patient's interests, a quick internet search or a call to a local refugee assistance agency could yield a variety of options for your patient.

- Perhaps your patient has well-developed skill areas that they would like to contribute to the community. Volunteer matching websites have suggestions with many ways for people to volunteer their time and skills to improve the community at large. Some patients will prefer to gain social contacts through serving an agency rather than being served by one.
- Don't assume affinity between members of the same group.
- Help patients to strategize things to say if they encounter uncomfortable questions in new relationships. Reassure patients that they do not have to disclose their trauma as they get to know someone. CVT providers often describe for patients how, even in the United States, the early stages of friendship involve small talk, finding common interests and doing activities together. Deep disclosures can come with a deeper friendship, and it is okay to set boundaries around sensitive topics.

### EXAMPLE

CVT providers worked with a woman who experienced domestic violence for many years at the hands of her husband. As part of the abuse, her husband would tell her on a regular basis that she was crazy. She felt he must have been right because she was working with one of our psychotherapists and social workers. Through treatment, she began to feel stronger and less shame about her symptoms. She began to initiate conversations with a few other women at her place of employment who spoke her language. She eventually began sharing her experiences with them about the situation with her husband. Somewhat to her surprise, her coworkers were supportive of her and that she was seeking help. They helped her realize she would be okay and actually better off without her husband. She reported to her providers how good it felt that she did not have to hide parts of herself to her coworkers, who ended up becoming dear friends. She actually encouraged one friend to seek out services at CVT.

## *Social Connections: Community*

Community implies connection — some combination of shared beliefs, circumstances, priorities or relationships. When working with refugee communities, it is important to keep in mind that these connections that bind people together may or may not be rooted in place. Therefore, community connections need to be thought of to include your immediate community and its resources, the broader community of refugees in the United States and community connections in the home country and refugee camp. Providers can refer to all of these levels of community when planning for health and wellbeing.

Refugee communities include the families and friends discussed earlier in this chapter. Other parts of the refugee community include cultural connections, such as faith or ethnic communities; circumstantial connections, such as neighborhoods or socioeconomic connections; and functional connections, such as service organizations and health care facilities. Community connections in each one of these areas are important to address because of the ways in which our environment impacts our health and wellbeing. It is difficult to ask someone to change or heal without addressing their circumstances.



When working with refugees, it is important to first assess their level of connectedness in the community. The types of traumatic experiences that refugees face often make it difficult to trust others, even for many years. One of the core elements of posttraumatic stress is a fear of going out of the house. For example, many refugees will report a fear of taking the bus or train because someone might attack them while they are out. Additionally, they may fear that if this does happen, they will not be able to ask for help because they do not speak the language or understand cultural norms. Providers working with refugees need to bear in mind the impact of traumatic stress when making recommendations to go out in the community, or when making a referral to a new clinic or agency.

## RECOMMENDATIONS

- Ask patients what formal and informal connections they already have. Find out about the refugee communities in your area and what community programs exist. For example, there are 8,000 Karen refugees in Minnesota, making it a well-established community. With such a large diaspora, many formal and informal community networks already exist and can be accessed by providers. This may differ depending on location and existing community.
- Ask your refugee patient, “If you were back home, who would you go to for help with this problem?” This will shed light on types of possible community support, such as faith communities or elders. Try not to dismiss community supports that might feel unfamiliar to you, such as community healers or elders’ counsels. Rather, engage those supports in problem solving. Examples of community leaders include religious leaders, traditional leaders such as shaman, leaders in the arts such as musicians and artists, elders and academic leaders.
- Often engaging community supports for Western providers requires a process of negotiation. Health care providers should remain open to community supports and interventions, while providing information about how different issues are addressed in the United States. This allows a refugee patient the chance to draw both from culturally familiar services as well as new services available in the United States.

### EXAMPLE

A woman from a Middle Eastern community shared an instance of domestic violence with a physician. The physician asked how these issues would be resolved in her home country. She reported that usually the couple will meet with local elders to discuss the issue and see if a resolution can be found. The concerned physician acknowledged this, and also told the patient about local shelters and domestic violence organizations. They agreed together that the patient would first go to elders to seek mediation with her husband. They also scheduled a follow up appointment to see how things were going. If mediation didn't work, the patient agreed she would like to make an appointment with the organization the doctor recommended.

- Maintain openness to differences in community dynamics. For example, there may be differences in gender roles or family structure in each refugee community. Try to remain open to understanding these differences.
- Connecting with community and family back home can be a source of both strength and stress. For example, refugees may be separated from loved ones, and finding ways to connect via phone or social media can help your patient feel more connected to home. However, sometimes news, photos or videos of violence and conflict back home can be a trigger for past trauma. Talk with your refugee patient about how to create balance—for example, by limiting news and videos of violence before bed, which might lead to sleeplessness and nightmares. Recommend setting aside limited time during the day to catch up on news.

- Keep in mind ethnic diversity within a community. Sensitive ask how someone might identify ethnically and consider that when making referrals. For example, there may be many different ethnic groups resettled from one community. Finding social service organizations or community providers that offer services specifically to one culture can be a great resource. However, if your patient holds a differing identity, these referrals may not be a success.

### EXAMPLE

A provider was working with an Ethiopian patient who was unemployed. The provider recommended the patient go to the local Ethiopian cultural organization to meet with someone who is from his country and understands his experience. However, this patient identifies as Oromo, and the community organization is run by Amharic staff. The patient only speaks the Oromo language and did not feel comfortable working with an Amharic social worker, so he did not attend the appointment. However, there is a local case management organization that employs an Oromo worker and has Oromo interpreters available when a language match cannot be made. In this situation, the general case management referral was a better fit for this patient than the culturally-specific organization due to ethnic differences.

- Keep in mind religious diversity within the community. Similar to ethnicity, there can be significant religious diversity within a community. Churches, mosques and temples can be significant sources of social and economic support, as well as healthy coping. When in doubt, respectfully ask about a patient's faith preferences before recommending this as a primary support.
- Make referrals to community services that already exist: Providers can research local organizations that have been working with this community and use those as a referral source. If you are working with a newly arrived community, do some research on cities where there may be an established community and ask for recommendations. Such recommendations could include the following:
  - › Cultural organizations.
  - › Social service organizations.
  - › Resettlement offices.
  - › Schools.
  - › Employment organizations.
  - › ESL programs.
  - › Blind or hearing-impaired services.
  - › Know your rights programs.
- Identify cultural brokers and community liaisons. Make connections with individuals and groups that can assist you in understanding the local community and being supportive. These may be formal supports, such as teachers, or informal supports, such as a community member who is well respected.
- Utilize social workers in your clinic for community referrals. If your clinic does not have a social worker, connect with an outside organization and establish a relationship with a social worker for referrals.
- Be open to developing nontraditional health interventions. One of the benefits of working with refugee communities is the ability to creatively design culturally appropriate interventions. For example, consider sewing groups, gardening groups or parenting groups, among others.
- Listen for patterns in community problems and tailor interventions to the community need. For example, there may be a prevalence of substance use, domestic violence or issues such as deportations. Be responsive to these



community-level needs when tailoring interventions. Work in partnership with other local organizations when needs are outside your expertise.

- The cultural community in the United States may be foreign and unfamiliar to your refugee patient. Interventions that assist in navigating the new community can be extremely effective.
  - › Consider providers or volunteers that can assist refugee patients in navigating transportation. Sometimes reviewing maps and directions is sufficient. Sometimes, however, having someone go along to assist with unfamiliar systems is most effective.
  - › When referring a patient to a new location, assess a patient's familiarity with the location and distance from their home. Take the time to walk through directions and make a plan for transportation with the patient to ensure that he or she can safely make it to the appointment. Show the patient a photo of the location (often accessible on Google Maps or an agency's website). Print the photo for the patient to take along to show someone in case they get lost.
  - › Consider warm handoffs and accompaniment when possible. It may ease many stressors to have a supportive provider make an introduction to a new referral or attend the first appointment together.
  - › Consider very practical barriers to engaging with the community: Does your patient have the proper clothing? If you live in a place with severe winters, does your patient have access to a winter coat and boots in order to go outdoors?

### EXAMPLE

A therapist working with a patient from East Africa noticed that he came to session week after week in sandals, despite the cold weather outside. The therapist inquired if the patient owned boots, and he revealed he had never owned boots and did not know how to shop for them. The therapist and patient spent some time in session looking at winter boots online, identifying aspects that made a quality boot for the local winter climate. The patient came back the following week wearing the boots he purchased. He reported he felt more comfortable going out to visit friends and to the gym because he no longer worried about his feet freezing. He described a better mood and less isolation with his new shoes, both improvements in depressed mood.

### EXAMPLE

A social worker was working with a new client from a rural village in West Africa. The client told her she had been in the United States for more than a year but had never left the house because she was too scared of getting lost or hurt. She wanted to go downtown to meet with a lawyer but had missed several appointments due to fear. The social worker assessed for her familiarity with transportation and quickly learned that the client's only experience with transportation was her flight to the United States. The social worker accompanied her client to an appointment with the lawyer, leaving early to teach the transportation system. On the trip, the client reported this was her first time on a bus, on a train and riding an elevator. The social worker patiently explained how to count stops on the bus and how to push the button for your floor in the elevator. With practice, the client was eventually able to make the trip to her lawyer independently for her immigration case.





## *National Sociopolitical Context*

In addition to navigating relationships with family, friends and community members, refugees engage with the sociopolitical context as they resettle in the United States. National-level conversations about immigration can be challenging for refugees to follow. When refugees hear news about policy changes related to immigration, they may not know what applies to them and what applies to other categories of immigrants. This confusion can cause worry about a variety of issues, such as the path to citizenship, access to family reunification, availability of public benefits and what services they can receive. Additionally, national rhetoric about immigration issues impacts the extent to which refugees feel at home and safe (or not) in the United States. Of course, when xenophobic rhetoric is prevalent in the national sphere, this can increase the stress experienced by refugees and worry about their safety in the United States.

While federal policies set standards for levels of public support available to refugees, each local community may develop specific services and supports for refugees. The policies that impact service and benefit availability are ever-changing. It can be daunting to keep up with exactly which programs are open to refugees or asylum seekers at any given time. For example, a refugee with permanent residency status who receives SSI due to a disability is no longer qualified to receive this benefit after living in the United States for seven years as a noncitizen. Even those on the path to citizenship may experience loss of this benefit as they wait for the often lengthy citizenship process to complete. For many refugees with a disability, SSI is the only source of income; the loss of this benefit is detrimental to their financial stability and may also impact physical health and mental health.



### RECOMMENDATIONS

You will notice your patients experiencing barriers to getting services or encountering discrimination that impacts their care. It can be tempting to want to dig in and fix these large systemic challenges for your patients. As a provider it is important to know that an array of policies, attitudes and cultural dynamics impact your patients' health and well-being. However, you do not need to be the expert on these policies. In fact, refrain from giving any advice or guidance in the policy realm unless it is your area of expertise. Most importantly, do not give legal advice to your patients unless you work in the legal field.

It is important for your clinic to develop relationships with community agencies whose role it is to ensure access to services for refugees. These referrals are essential to ensuring that your refugee patient has stable housing, income, and health insurance. Often these agencies have attorneys on site to give legal advice about immigration, housing and employment discrimination, and public assistance access. Some clinics even choose to partner with local refugee resettlement agencies or legal aid agencies to help refugees problem solve access needs on site.

Finally, though you cannot easily change the social, political and cultural dynamics your patients encounter, you can make your setting a warm, welcoming place for refugees and asylum seekers. Your caring presence offers a counter-narrative to negativity your patient may encounter in the local community or national dialogue.

## SUMMARY OF RECOMMENDATIONS

- Hire social workers (if you don't already have them) to help clients navigate social supports and community relationships. If you cannot hire social work staff, establish relationships with local social service agencies and refer accordingly.
- For patients separated from family, refer to immigration attorneys if there is a question about ability to reunite. Facilitate communication if possible via donated phone cards, etc.
- For families resettled together, become aware of family dynamics. If there is strain, normalize and provide education. Consider whether family members should be present in appointments. Sometimes it is helpful (e.g., a spouse of a patient who can help with reminders to take medications). Sometimes it is not (e.g., discussing details of a trauma in front of a child).
- Assess patient's social relationships outside of family both back at home, in the refugee camp and now. Familiarize yourself with local community groups and volunteer networks and refer if and when a patient is ready.
- Assess patients' involvement with the wider community. Ask who they would have gone to back home for problems. Familiarize yourself with social service agencies, cultural brokers, etc., and when making a referral, ensure it is a warm hand-off, not simply giving a name and a phone number.
- Don't offer legal advice when a client has been discriminated against; refer to legal organizations who offer this help. Be warm and welcoming.

### CASE EXAMPLE: RESOLUTION

- SW:** *[Hanging up from conference call with a pro bono immigration attorney] Paw, did that make sense, what the lawyer said?*
- Paw:** *She said I can apply for my daughter once I get citizenship. She said it could take many, many years.*
- SW:** *Yes, that is what I heard too. What do you think of this information?*
- Paw:** *I am sad that I might not see my daughter for a very long time, but happy to hear that it is possible for her to come here. I thought I might never see her again.*
- SW:** *That makes sense to me that you have mixed feelings. I am glad that you have more information.*
- Paw:** *Yes, me too.*
- SW:** *Another thing we talked about last week was talking to the therapist about your ex-husband and how he hurt you. Did you get a chance to do that?*
- Paw:** *I did. Lisa was very nice. She listened to me. And she didn't make me feel dumb or crazy. That was not a good time for me. I am glad I don't see him.*
- SW:** *Have you thought any more about doing some more things outside the apartment?*

- Paw:** *A little bit. It is very boring being home all day long by myself. I did say “hello” to one of my neighbors when I saw her in the hall and she stopped and talked to me for a few minutes. I learned she came from a camp near my camp and we know some of the same people. She asked me to come have tea next week. I am scared but I might try.*
- SW:** *It can be really scary to talk with people you don’t know for the first time, especially when you have these negative thoughts in your head from your ex-husband.*
- Paw:** *I want to try to get him out.*
- SW:** *How about the church you talked about last week, any more thoughts about going there?*
- Paw:** *I have thought about it. I am not sure yet. I am still scared.*
- SW:** *I think it is great you are thinking about it and I also think it is okay to take your time. We can work on this little by little!*
- Paw:** *Yes, little by little.*

## DISCUSSION QUESTIONS

*Consider your current role as a provider:*

- › Who assesses and intervenes with social connection at your clinic? What is your relationship with this provider, and do you see opportunities for increasing collaboration?
- › What is your knowledge of resources within or outside the clinic for patients to increase community engagement?
- › What do you do when a patient arrives with a family member? How do you determine when to invite a patient’s family member or friend into a session?

*Imagine you are in Paw’s position as a patient:*

- › Do you view reunification with your daughter as contributing to your health? Why or why not?
- › How would you want your social worker, primary care doctor, or therapist to inquire about your social support given your current sense of isolation? What would you find helpful?

## References

Center for Victims of Torture. (2005). *Healing the hurt*. Retrieved from <https://www.cvt.org/resources/publications>.



# Mitigating Secondary Trauma

## CHAPTER 10

### CASE EXAMPLE

**MD:** *[Sees Lisa in the hallway between patients] Hey Lisa, can I talk to you for a minute about a mutual patient?*

**Lisa:** *Sure, I only have two minutes before my next appointment, but go ahead.*

**MD:** *It's about Paw. When the administration started this new medication adherence quality metric, they started sending me reports on Paw and my other Karen patients. They are not refilling their prescriptions as I have prescribed them and I am getting a low rating. Every time she comes in she complains of pain and headache. I've done all the tests there are to do and I think I've prescribed the most appropriate medication. But she's not taking it. I want to throw my arms up; she keeps coming back with the same complaints but then won't follow my advice.*

**Lisa:** *I have also been thinking about Paw lately. I couldn't sleep last night thinking about what she went through and how much she is still struggling. I feel like I am not able to help her very well. I have been meeting her for over nine months now and it doesn't really seem like she has improved very much. Sometimes I feel like I don't know what I am doing or I am not good at my job.*

**MD:** *It's not you, it's her! She doesn't seem to be listening or trying. I think she wants a magic pill to just fix everything and I keep explaining that doesn't exist. She needs to make some effort on her part, otherwise I give up.*

**Lisa:** *Maybe we should talk about her case at the next care conference. Sounds like we could both use some help with the case.*



## Introduction

*Secondary trauma (like the related concepts of vicarious trauma and compassion fatigue) is the effect on helping professionals working with trauma survivors. It is different than burnout, which is associated with the more general stress and fatigue of work across all types of different jobs. Secondary trauma stems from working with trauma survivors and being witness to their past experiences and current life stressors. Professionals working with refugees will experience secondary trauma. The primary care setting, with its fast pace and high volume of patients, is one that makes a professional particularly vulnerable to struggling with secondary trauma. This chapter defines secondary trauma and its effects; discusses ways professionals working in primary care with refugees can take care of themselves and take care of each other on a team; and explores how secondary trauma and burnout can and must be mitigated at the organizational level.*

## Defining Secondary Trauma

Over the past 20 years, increasing attention has been given to the phenomenon called **secondary trauma** and other closely related concepts such as vicarious trauma and compassion fatigue, effectively increasing awareness for helping professionals.

According to the Center for Victims of Torture (2005), “Among providers working routinely with extreme trauma such as torture, secondary trauma is considered to be an occupational hazard—something that can be reduced and managed, but not avoided completely.” Secondary trauma affects the provider’s work both with the patient and with colleagues, in addition to life outside of work. Furthermore, for providers who have themselves experienced primary trauma, the work can trigger reactions related to their own history.

While a health care provider may not always seek out an individual refugee’s trauma story, stories will emerge depending on the patient and the provider’s style of practice. In fact, as described earlier, understanding a patient’s past trauma experiences is often essential to have a complete picture of current symptoms and how to help. As such, providers will be exposed to painful stories. In addition to past trauma, as described in Chapter 5, many refugees struggle with a myriad of current stressors. It is very easy for providers to feel some of that same overwhelm and helplessness, particularly if they do not have anything immediate to offer to alleviate those stressors (as is commonly the case). This exposure is compounded by the volume and speed at which providers are increasingly directed to provide care.

Secondary trauma stems directly from hearing patients’ traumatic experiences. **Burnout** is different but can coexist with secondary trauma.

Anyone in any profession can experience burnout, and it is a pressing phenomenon in the medical community. A report in *The Atlantic Monthly* detailed the growing challenges in medicine, including a system whereby doctors need to

### DEFINITION

#### **Secondary Trauma:**

*The effects of being exposed to trauma indirectly through others; service providers often experience unexpectedly strong feelings—or numbness or shock—when talking about torture or hearing survivors’ stories. (Center for Victims of Torture [CVT], 2005)*

### DEFINITION

#### **Burnout:**

*A response to a broad range of occupational stressors and chronic tediousness in the workplace, often characterized by symptoms such as emotional exhaustion, depersonalization or a lack of personal accomplishment (Shoji, August 15, 2015).*



see a large number of patients in a day to offset lowered insurance reimbursement rates. The required level of paperwork increases the problem: the administrative duties of the job leave doctors with just 12 to 17 percent of their day to spend with patients (O'Rourke, 2014). Doctors' morale and optimism about their profession has plunged in recent years, and rates of suicide among doctors are higher than any other professional group. (O'Rourke, November 2014).

## *Effects of Secondary Trauma*

CVT providers working with victims of trauma have expressed experiencing shock, outrage, sadness and intrusive thoughts and images outside of work. With experience, clinicians have shared they feel less and less shocked by client stories and have developed personal strategies to try to compartmentalize, or separate, work and home life. This compartmentalization is protective and can help sustain a provider over time, but it also creates the risk for the individual to become numb to patients and their stories. The effects of secondary trauma over a long period can become less obvious and more insidious; for example, rather than regular nightmares, a provider may slowly start to see the world as a more dangerous place and begin to avoid travel or initiating new relationships. The exact manifestations of secondary trauma will depend very much on one's individual characteristics and life experiences. It is inevitable, however, that providers will be changed by this work.

Not all of these changes are negative. Providers seek out this type of work for a reason. Each person's reason is different, but working with survivors of trauma is also an incredibly rewarding experience. At CVT, refugee clients express incredible gratitude for the work of providers, who are sometimes the only person a survivor has trusted with their story. Providers have the opportunity to develop relationships with inspiring patients and to watch as patients improve and reconnect with their lives. This work can remind us of our common humanity. It can help us to keep our own problems and worries in perspective. Hernandez, Gangsei and Engstrom (2007) coined the term vicarious resilience to reflect these positive experiences. They found "witnessing and reflecting on human beings' immense capacity to heal and reassessing the dimensions of one's own problems were the most common themes in this regard." (Hernandez et al., 2007, p.238).

## **RECOMMENDATIONS FOR INDIVIDUAL PROVIDERS**

The first, and often most challenging, aspect of mitigating secondary trauma for an individual is to be aware that it is happening. It is easy and often protective for a certain amount of time to try to avoid thinking about how you are doing and feeling about your work and your patients. Secondary trauma can be sneaky; it can creep up on you and come out in ways that are unexpected. You may have heard a number of trauma stories from patients or listened to their current stressors with relative ease only to find that you are quite irritated with your partner for complaining about the hard day they had at their desk job. Or you might find yourself feeling tense and irritated and you are not quite sure why. You might speak more brusquely to a colleague than you normally would. Or, you might find yourself declining more and more invitations to social activities. Understanding where these reactions come from is an important first step in mitigating the effects of secondary trauma.

There are many different ways individuals can take steps to become aware of their reactions. One tool staff at CVT have found helpful is the Professional Quality of Life Elements Theory Measurement survey (Hudnall Stamm, 2009). Taking the survey every few months is a way to stay aware and in touch with your current work experience. The ProQOL is included here with instructions for scoring (note that compassion satisfaction is similar to vicarious resilience, discussed above).



# Professional Quality of Life Scale (ProQOL)

*Compassion Satisfaction and Compassion Fatigue  
(ProQOL) Version 5 (2009)*

When you [help] people you have direct contact with their lives. As you may have found, your compassion for those you [help] can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a [helper]. Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the last 30 days.

**1=Never**

**2=Rarely**

**3=Sometimes**

**4=Often**

**5=Very Often**

- \_\_\_\_\_ 1. I am happy.
- \_\_\_\_\_ 2. I am preoccupied with more than one person I [help].
- \_\_\_\_\_ 3. I get satisfaction from being able to [help] people.
- \_\_\_\_\_ 4. I feel connected to others.
- \_\_\_\_\_ 5. I jump or am startled by unexpected sounds.
- \_\_\_\_\_ 6. I feel invigorated after working with those I [help].
- \_\_\_\_\_ 7. I find it difficult to separate my personal life from my life as a [helper].
- \_\_\_\_\_ 8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I [help].
- \_\_\_\_\_ 9. I think that I might have been affected by the traumatic stress of those I [help].
- \_\_\_\_\_ 10. I feel trapped by my job as a [helper].
- \_\_\_\_\_ 11. Because of my [helping], I have felt "on edge" about various things.
- \_\_\_\_\_ 12. I like my work as a [helper].
- \_\_\_\_\_ 13. I feel depressed because of the traumatic experiences of the people I [help].
- \_\_\_\_\_ 14. I feel as though I am experiencing the trauma of someone I have [helped].
- \_\_\_\_\_ 15. I have beliefs that sustain me.
- \_\_\_\_\_ 16. I am pleased with how I am able to keep up with [helping] techniques and protocols.
- \_\_\_\_\_ 17. I am the person I always wanted to be.
- \_\_\_\_\_ 18. My work makes me feel satisfied.
- \_\_\_\_\_ 19. I feel worn out because of my work as a [helper].
- \_\_\_\_\_ 20. I have happy thoughts and feelings about those I [help] and how I could help them.
- \_\_\_\_\_ 21. I feel overwhelmed because my case [work] load seems endless.
- \_\_\_\_\_ 22. I believe I can make a difference through my work.
- \_\_\_\_\_ 23. I avoid certain activities or situations because they remind me of frightening experiences of the people I [help].
- \_\_\_\_\_ 24. I am proud of what I can do to [help].
- \_\_\_\_\_ 25. As a result of my [helping], I have intrusive, frightening thoughts.
- \_\_\_\_\_ 26. I feel "bogged down" by the system.
- \_\_\_\_\_ 27. I have thoughts that I am a "success" as a [helper].
- \_\_\_\_\_ 28. I can't recall important parts of my work with trauma victims.
- \_\_\_\_\_ 29. I am a very caring person.
- \_\_\_\_\_ 30. I am happy that I chose to do this work.



## WHAT IS MY SCORE AND WHAT DOES IT MEAN?

In this section, you will score your test so you understand the interpretation for you. To find your score on **each section**, total the questions listed on the left and then find your score in the table on the right of the section.

### Compassion Satisfaction Scale

Copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

3. \_\_\_\_\_  
6. \_\_\_\_\_  
12. \_\_\_\_\_  
16. \_\_\_\_\_  
18. \_\_\_\_\_  
20. \_\_\_\_\_  
22. \_\_\_\_\_  
24. \_\_\_\_\_  
27. \_\_\_\_\_  
30. \_\_\_\_\_

**Total:** \_\_\_\_\_

The sum of my Compassion Satisfaction questions is	So My Score Equals	And my Compassion Satisfaction level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

### Burnout Scale

On the burnout scale you will need to take an extra step. Starred items are “reverse scored.” If you scored the item 1, write a 5 beside it. The reason we ask you to reverse the scores is because scientifically the measure works better when these questions are asked in a positive way though they can tell us more about their negative form. For example, question 1. “I am happy” tells us more about

\*1. \_\_\_\_\_ = \_\_\_\_\_  
\*4. \_\_\_\_\_ = \_\_\_\_\_  
8. \_\_\_\_\_  
10. \_\_\_\_\_  
\*15. \_\_\_\_\_ = \_\_\_\_\_  
\*17. \_\_\_\_\_ = \_\_\_\_\_  
19. \_\_\_\_\_  
21. \_\_\_\_\_  
26. \_\_\_\_\_  
\*29. \_\_\_\_\_ = \_\_\_\_\_

**Total:** \_\_\_\_\_

The sum of my Burnout Questions is	So my score equals	And my Burnout level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

You Wrote	Change to
	5
2	4
3	3
4	2
5	1

the effects of helping when you are *not* happy so you reverse the score

### Secondary Traumatic Stress Scale

Just like you did on Compassion Satisfaction, copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

2. \_\_\_\_\_  
5. \_\_\_\_\_  
7. \_\_\_\_\_  
9. \_\_\_\_\_  
11. \_\_\_\_\_  
13. \_\_\_\_\_  
14. \_\_\_\_\_  
23. \_\_\_\_\_  
25. \_\_\_\_\_  
28. \_\_\_\_\_

**Total:** \_\_\_\_\_

The sum of my Secondary Trauma questions is	So My Score Equals	And my Secondary Traumatic Stress level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High



## YOUR SCORES ON THE PROQOL: PROFESSIONAL QUALITY OF LIFE SCREENING

Based on your responses, place your personal scores below. If you have any concerns, you should discuss them with a physical or mental health care professional.

### Compassion Satisfaction \_\_\_\_\_

Compassion satisfaction is about the pleasure you derive from being able to do your work well. For example, you may feel like it is a pleasure to help others through your work. You may feel positively about your colleagues or your ability to contribute to the work setting or even the greater good of society. Higher scores on this scale represent a greater satisfaction related to your ability to be an effective caregiver in your job.

The average score is 50 (SD 10; alpha scale reliability .88). About 25% of people score higher than 57 and about 25% of people score below 43. If you are in the higher range, you probably derive a good deal of professional satisfaction from your position. If your scores are below 40, you may either find problems with your job, or there may be some other reason—for example, you might derive your satisfaction from activities other than your job.

### Burnout \_\_\_\_\_

Most people have an intuitive idea of what burnout is. From the research perspective, burnout is one of the elements of Compassion Fatigue (CF). It is associated with feelings of hopelessness and difficulties in dealing with work or in doing your job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that your efforts make no difference, or they can be associated with a very high workload or a non-supportive work environment. Higher scores on this scale mean that you are at higher risk for burnout.

The average score on the burnout scale is 50 (SD 10; alpha scale reliability .75). About 25% of people score above 57 and about 25% of people score below 43. If your score is below 43, this probably reflects positive feelings about your ability to be effective in your work. If you score above 57 you may wish to think about what at work makes you feel like you are not effective in your position. Your score may reflect your mood; perhaps you were having a “bad day” or are in need of some time off. If the high score persists or if it is reflective of other worries, it may be a cause for concern.

### Secondary Traumatic Stress \_\_\_\_\_

The second component of Compassion Fatigue (CF) is secondary traumatic stress (STS). It is about your work related, secondary exposure to extremely or traumatically stressful events. Developing problems due to exposure to other's trauma is somewhat rare but does happen to many people who care for those who have experienced extremely or traumatically stressful events. For example, you may repeatedly hear stories about the traumatic things that happen to other people, commonly called Vicarious Traumatization. If your work puts you directly in the path of danger, for example, field work in a war or area of civil violence, this is not secondary exposure; your exposure is primary. However, if you are exposed to others' traumatic events as a result of your work, for example, as a therapist or an emergency worker, this is secondary exposure. The symptoms of STS are usually rapid in onset and associated with a particular event. They may include being afraid, having difficulty sleeping, having images of the upsetting event pop into your mind, or avoiding things that remind you of the event.

The average score on this scale is 50 (SD 10; alpha scale reliability .81). About 25% of people score below 43 and about 25% of people score above 57. If your score is above 57, you may want to take some time to think about what at work may be frightening to you or if there is some other reason for the elevated score. While higher scores do not mean that you do have a problem, they are an indication that you may want to examine how you feel about your work and your work environment. You may wish to discuss this with your supervisor, a colleague, or a health care professional.



Once aware of how you are impacted by secondary trauma, the next step is to determine how to mitigate it. A great deal of research on secondary trauma highlights the importance of self-care outside of the work place. Often self-care strategies are presented as a somewhat exhaustive (and potentially exhausting) list of things we need to be doing to take care of ourselves. The standard list includes suggestions such as get 8 hours of sleep, avoid caffeine, have a healthy diet, exercise multiple times a week, do yoga, meditate, take naps, avoid alcohol, don't smoke, be social, relax, do something creative, spend time outdoors, etc. Lists like this may be helpful for some but also may be overwhelming and have the potential to serve as a reminder of all of the things we are not currently doing. If that's the case, consider choosing one or two strategies to focus on, rather than trying to do them all and potentially setting yourself up for disappointment or failure. In addition, recommended self-care activities are often very individualistic in nature and may not appeal (or be possible for a myriad of reasons) for providers who come from the collectivist cultures that many refugees do. In either case, focus on activities or experiences that bring you joy, or peace, or energy, or whatever it is that makes you feel grounded and alive. These may be things you've stopped doing, or things that you've never tried before. Conversely, saying no to taking on additional activities can also be an important part of self-care.

Finding colleagues who can offer support and empathy is also a crucial strategy for those working with refugees and torture survivors. The CVT's (2005) advice for psychotherapists is also applicable for other providers working in primary care with refugees:

*Psychotherapists working with torture commonly feel as though they do not have access to peers who understand them or can relate to their particular stresses, struggles, and dilemmas. Sustaining connection with sources of professional and personal support is extremely important in attending to the effects of the work on the mental health provider. Developing collegial relationships with other therapists from torture treatment programs around the country is uniquely and profoundly helpful in addressing the reality of professional isolation. (p.71)*

It is also important to find ways to take care of yourself within the workday. In an ideal situation, providers have some control over their workday schedule and caseload. In primary care, however, this is not likely to be the case. If you cannot control how many patients you see in a day or when you see them, are there very small pieces of time you can control? For example, can you take a minute between patients to do a short breathing exercise or walk around in the halls? Can you block off time for lunch every day and then create a strict boundary to not do work during this time?

Consider asking for bigger changes if needed, such as cutting down the workweek to four days to avoid work consistently spilling into weekends. Of course, not everyone has the financial or workplace flexibility to adjust their work hours. And particularly if you are a provider who comes from the refugee community with whom your work, there may be expectations for you to continue to work and advocate for community members outside of work, in the evening or during the weekends. There may be community reaction or response if you do not live up to these expectations. This may intensify your own work, sense of fatigue, and secondary trauma in ways other providers may not appreciate or fully understand. Be gentle with yourself, and focus on self-care strategies that help sustain you and bring you energy.

The experience of secondary trauma is also impacted by providers' sense of themselves in relation to their work. Tobey (personal communication, October 6, 2018) describes three stances providers can take when serving survivors of trauma. Understanding the difference can be a key in coping with secondary trauma. They are as follows:

- **Hyper-personalized:** In this stance your identification with work is complete; you become work and work is an expression of you. You are the hero—it's all happening to you. Your client, your client's family, your client's eviction, your client's job loss. Most all achieving people can find themselves functioning in this stance and love it for a while. Sometimes a victim's trauma or life situation will so remind you of your own that it is hard not to overly identify with them. There is richness to the work when our relationship is overly personal. You can experience yourself as so vital to those you serve, and you may experience your work with your clients as so critical for privately informing you about whom and what you are. The work can represent the great drama of your life. But secondary trauma symptoms afflict those who are connected to their work in this hyper-personalized way.



- **De-personalized:** In this mode, the work ceases to have any relationship to you or who you are. Once depersonalized, the work becomes empty, and you feel shut down. This is certainly the stance of someone experiencing burnout. Perhaps some you have even specifically sought out this work because your previous job had become depersonalized for you.
- **Non-personal:** In this stance, you find a way to do the work without the subjective feeling that it is all about you. Things—good or bad—can just happen without it all having to happen to you through you or because of you. In this non-personal stance, you can find a distance from which to witness the work being done, knowing that you have done what was within your control.

In hyper-personalized mode, there is no separation between the self and work, and thus it is hard to step away from it to witness it. In the de-personalized state the separation is so great that there is little interest that witnessing. In the non-personal stance, there is enough separation that you can witness your clients as they experience what they have to experience, and with this separation comes less frustration and anger, and perhaps less the sense of heroic righteousness—and less potential for the sense of personal failure. The non-personal stance is more sustainable over time and more effective. Shifting to this mode might be obvious for some; for others it entails a big change in thinking and a different way of being present in work and in their world. It does not require you to not care; of course you want to end the suffering you encounter, but you can also simultaneously realize the value in avoiding your personal attachment to the outcome. (H. Tobey, personal communication, October 6, 2018).

It is important to understand your own motivations for being drawn to the work. A consulting psychiatrist at CVT once said to a team of psychotherapists, “You know the reason you are all here doing this job is because you are really trying to help yourself or someone in your family.” There was a deafening silence—suggesting a surprised recognition—after she made this comment. Understanding your motivations for doing the kind of work you do may take time and is likely to shift. But this understanding can facilitate your ability to take a non-personal stance toward the work, which is a significant factor for mitigating secondary trauma.

## RECOMMENDATIONS FOR TEAMS

Coping with secondary trauma should not be an individual activity. Your coworkers, in many ways, are key partners. Working in a high-volume environment with traumatized and often low-resourced patients is something that friends and family (and the general public) working outside the field may not understand. Coworkers do understand and can be key sources of support both within the workplace and outside.

Within the workplace, consultation between providers about shared clients is critical for care coordination. It is also an important way in which providers can support each other. Taking the opportunity to talk as a team about patients, particularly ones that providers find challenging, is a crucial way to mitigate secondary trauma experiences of isolation, helplessness and failure. While it requires time that you aren’t billing and seeing patients, in the end, consultation can be a time-saver not only for coordination purposes, but also for bolstering staff to feel understood and supported. At CVT, providers set aside 90 minutes each week to discuss cases as a team. While this may not be possible in a primary care setting, it is ideal to dedicate at least an hour or two each month to this activity.

If you and your team already have a mechanism to discuss cases, how you talk about cases is important. Providers who raise questions in a consultation can feel overwhelmed if everyone jumps in and offers recommendations, especially if they are infeasible or impractical. Lansen and Haans (2004) offer a consultation method that providers at CVT have found useful for many years. Listeners imagine they are in the position of both the patient and the provider presenting the case. This method often helps teams get to underlying questions and reactions they may not even be aware of, and helps providers to feel understood by their colleagues. It takes between 20 and 30 minutes to use this method, a consideration for a busy primary care clinic. Directions for this method are included here.





## *Lansen and Haans Method*

### **Note to Facilitator:**

- *Be active in holding the group to the method; don't be a passive listener.*
  - *Intervene as needed during the "questions of clarification" step when members stray into making comments (as opposed to asking questions) or asking nonfactual questions (such as hypothetical questions).*
  - *Redirect members as needed to identification of feelings/thoughts/experiences in the identification steps.*
- 

### **Step 1: Choose a Case**

Group decides which case(s) to discuss that day, based on the consultation/supervision questions identified by the members (this takes time, but is an important group task).

### **Step 2: Presentation of Case by Provider(s)**

Presenting provider(s) provide a brief background of the client along with the question for consultation. Group listens without comment/interruption.

### **Step 3: Factual Questions From Group**

Factual questions of clarification are asked by group members. Facilitator closes this stage by asking group members, "Have you have asked enough questions to be able to identify with this client and identify with the task/position of the provider(s)?"

### **Step 4: Identification With Client**

Facilitator instructs group members, "Take a minute to imagine that you are this client with these issues. Notice your thoughts/feelings/body sensations." After a minute of silence, facilitator asks group members to express what they're willing to share about what they've noticed by saying, "I am [client's name], and I ...." Providers listen and do not take notes, focusing on attending to their own thoughts/ feelings /sensations in response to group members' associations. Facilitator closes this stage by asking the presenting provider(s) to share impressions: "What did you notice as you heard your colleagues reflect?"

### **Step 5: Identification With the Task and Position of the Provider(s) (not with the provider as a person)**

Facilitator instructs group members, "Take a minute to imagine that you are the providers working with this client. Notice your thoughts/feelings/body sensations." After a minute of silence, the facilitator invites group members to express what they're willing to share about what they've noticed by saying, "I am in [providers' name(s)]'s position, and I ...." Providers listen and do not take notes, focusing on attending to their own thoughts/ feelings /sensations in response to group members' associations. Facilitator closes this stage asking presenting provider(s) to share their impressions: "What did you notice as you heard your colleagues reflect?"

### **Step 6: Taking Up the Consultation Question**

Group discusses the question of "What would you do?"

### **Step 7: Presenter Reflections and Next Steps**

Final round focuses on presenting provider(s) and addresses the question of "Which of the reflections/suggestions you've received help to address your consultation/supervision question, and what can you do with it?"





Informal opportunities to consult and debrief are also important. Talk to colleagues between patients or at the beginning or end of the day when you feel overwhelmed or stuck, like in the case example at the beginning of this chapter. Gathering with coworkers outside of work is another way to mitigate secondary trauma. Sometimes just being together with people who understand the daily challenges of work and having fun can help to mitigate secondary trauma.

## RECOMMENDATIONS FOR ORGANIZATIONS AND ADMINISTRATORS

No amount of yoga, napping and healthy eating can protect an individual provider from being stuck in secondary trauma if they are working for an organization that does not acknowledge and address secondary trauma. When providers work in situations like primary care clinics where they are required to see a high volume of patients, have significant paperwork responsibilities and face trauma and helplessness from their patients on a daily basis, the administration needs to care for employees or risk losing them. Turnover in primary care is significant and costly; it is estimated that the total cost of turnover of a single physician can be over \$800,000 (Fibuch, 2015). The concern is not only financial; compromised quality and safety, lower patient satisfaction, and negative personal consequences for the provider including suicidal ideation and chemical abuse are serious consequences of burnout on the job (Dyrbye et al., 2017).

Administrators should take time to proactively understand the specific needs of clinics serving refugees. CVT has seen primary care staff respond with frustration and irritation with across-the-board mandates from “above” did not seem to take in to consideration their population of refugee patients. For instance, in one organization, a decision was made to centralize the call-in system. The clinic where CVT providers worked had reception staff who spoke multiple languages and whom patients knew they could call and speak with directly. When centralization was proposed, staff worried that non-English speakers would not be able to manage a computerized system nor be able to successfully make an appointment with an English speaker. They predicted patients would just not call, then not come in and potentially let whatever ailed them to worsen. The clinic staff was able to share these concerns with management and, in the end, kept their phone system intact. Fortunately, this situation was resolved positively, though initially clinic staff members felt like their organization did not understand or care about their needs. Making sure staff feel heard and supported is a crucial way to mitigate secondary trauma and burn out at an organizational level.

Administrators should also acknowledge and normalize secondary trauma and burnout for staff members from the very beginning of a their time at the clinic. This way, providers hear from the organizational level that secondary trauma and burnout are real, normal and acknowledged experiences. CVT (2005) recommends that staff receive training on secondary trauma and have regular access to consultation. Training should include the following subjects:

- Signs and symptoms of secondary trauma.
- Contributing factors in the work itself.
- Contributing factors in the work environment.
- Contributing factors in the individual.
- Methods for addressing secondary trauma.

CVT (2005) stresses that support for addressing secondary trauma among interpreters, bicultural workers, and others from affected communities who have their own traumatic history is especially important: “Interpreters are in the position of hearing the trauma twice (in both languages) and interpret the trauma story. Establishing processes and procedures for screening, training, supporting, debriefing, and collaborating with interpreters in addressing secondary trauma is essential” (p.71).



Other more general recommendations that can help mitigate staff members' secondary trauma include ensuring the following:

- Adequate salary and time off (including R and R) for all staff members.
- Sufficient orientation, professional training and management supervision for staff members to feel competent and supported in their jobs.
- Plans for staff safety (including security training and briefing on security protocols).
- Access to medical and mental health support services.
- Positive connections among staff members, by working in teams, offering opportunities for socializing or offering peer support networks.
- Communication and contributions from staff members, by giving them a voice in decision making and feedback, providing information about why decisions are made (about resource allocations, policies, assignments, etc.), and looking for ways to build diversity and job enrichment into the work. (Headington Institute, 2008)

When setting up any organizational systems or supports to mitigate secondary trauma, be sure to ask for staff input about what kinds of activities and practices would be welcome. This is particularly important with a multicultural staff, as cultural norms around self-care are likely to differ and imposing one type or style of self-care practice at work risks alienating some staff members.

## SUMMARY OF RECOMMENDATIONS

- Individual level: Become aware of secondary trauma; use tools like the ProQOL. Participate in self-care activities that bring you joy, calm, rest and escape. Consider what stance you bring to your work and try to let go of your attachment to outcomes.
- Team level: Consult. Ensure there is a space and time to consult about difficult cases. Consider how you consult about cases; see the Lansen and Haans method described in this chapter for one method. Talk to your coworkers informally as needed; do fun things together outside of work on occasion.
- Administrative level: Take time to figure out the specific needs of primary care clinics serving large numbers of refugees. Acknowledge and normalize secondary trauma and build in training and other supports as detailed in this chapter.

### CASE EXAMPLE: RESOLUTION

Lisa and the doctor have a brief conversation following a care conference where they talked with other providers about Paw.

**MD:** *I had no idea Paw had told nurse Sharon how helpful she found our meetings and that she didn't know if she would be alive if she didn't have this clinic to go to.*

**Lisa:** *I was surprised by that as well. I think sometimes when we are so close to a case, it becomes difficult to see the progress and improvement.*



- MD:** *I have to admit, when Dr. Jones pointed out I seemed to be blaming the patient for my own sense of helplessness, that caused me to think a little bit.*
- Lisa:** *And for me I seem to be blaming myself.*
- MD:** *It was helpful other team members shared that they feel similarly a lot of the time.*
- Lisa:** *I liked the idea of forming a committee to set up some regular meetings where we can talk about secondary trauma. I am glad nurse Sharon agreed to take the idea to the manager to see how we could implement this given how little free time we have during the day.*
- MD:** *Yes, and it became clear to me during our conversation that I need to talk to the administration about this metric. It is not accurately evaluating positive change amongst our refugee patients, and it is not culturally competent practice to consider Western notions of success and compliance with our refugee clients. I do understand the need to measure change, but I think our clinic could come up with a more appropriate measure.*
- Lisa:** *Could we arrange a meeting together? I think together we can bring both of our perspectives to this and strengthen our point.*
- MD:** *That is great, thank you. I will set up the meeting. In addition to this, I think I need to get back to some of my practices that help me feel calm and centered and keep perspective. I really liked this yoga class I went to last year but then I stopped when things felt too busy. I need to get back to this.*
- Lisa:** *Yes, and I think I need to go on vacation. For more than like a day or two. I haven't gone on one for over a year and I haven't been using all my time off.*
- MD:** *I have my next patient, but thank you for talking about this with me. I am very glad we work on a team so we don't need to take this all on by ourselves.*

## DISCUSSION QUESTIONS

*Consider your current role as a provider:*

- › Considering the ProQOL, what element (i.e. Compassion Satisfaction, Burnout or Secondary Traumatic Stress) is more common for you? Why do you think that is? What strategies do you use to reduce compassion satisfaction and compassion fatigue?
- › What has been helpful in your organization to reduce secondary trauma from an organizational or self-care perspective? Do you see other opportunities for improvement?

*Imagine you are in Paw's position as a patient:*

- › How do you benefit when your clinic and/or provider utilizes practices to reduce secondary trauma? What is different for you as a patient?
- › How would you feel about your providers collaborating to offer support to each other regarding your care?



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