

Editorial

The meaning and the story: reflecting on a refugee's experiences of mental health services in Australia

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As the medical profession struggles to move into an evidence-based world there are many areas where the evidence for success is scanty and doctors need to listen to stories from their patients and colleagues to find ways of dealing with difficult issues. One of these areas is that of transcultural mental health and in particular the mental health of patients who come from a refugee background. The use of the patient's narrative of their illness as a means of diagnosis is championed by authorities from the field of narrative medicine,¹ but also by those who are developing the cultural formulation guidelines of the DSM-IV.² These writers discuss the importance of 'narrative competence' and of listening to patients' stories about what is happening to them,¹ including listening for information about their 'world-view, perspectives on self and body, and related mental health and social problems'² so as to obtain a deeper understanding of the patient's presentation from within their own cultural and societal context. The aim is to 'complement the multi-axial diagnosis of a person's health problems with a review of his or her cultural identity, experience of illness and help-seeking behaviour, social functioning and social supports based on cultural constructs and standards, and the potential cultural conflicts of the clinician-patient relationship'.² For refugees, who not only have cross-cultural hurdles to overcome but who also struggle with a higher burden of mental health issues, narrative can offer 'a method for addressing existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses'.³

Listening to Tarik's reflections about the difficulties he had as a refugee from Iraq negotiating the Australian mental health system and the solutions he suggests to overcome those difficulties is one way of beginning to develop this narrative competence.

When a patient comes as a refugee from the Middle East it is difficult to 'acknowledge' the place of a psychiatrist or psychologist. People would only see a counsellor, psychologist or psychiatrist (in the Middle East) if they are 'crazy' with psychosis or schizophrenia, or severely disabled. Depression and anxiety are seen as intellectual or spiritual problems, not mental health problems. There is a thought that psychological problems mean a person is stupid. If one person in a family has a mental health problem then this is a shame for the whole family and there may be discrimination and stigma. They may even have stones thrown at them at the market.

A person can't go to the doctor or talk to friends about it because of shame and the fear that they'd make fun of that person. There is also a lack of mental health hospitals and other help in Iraq. If they do see a doctor they do not want to talk and talk. This means that a person can't express himself, even with an interpreter. There is an expectation of medication as there is no culture of talking with health professionals. We have to tell things little by little – build up trust slowly.

When you treat a patient for a stomach problem, you are not just treating heartburn – only five minutes and a tablet is not treatment. You have to treat the whole of the person and listen to what they have to say about their life. There should be a

greeting of 'how are you, how is your family, how is your wife' – this is very important. One doctor just says 'take panadol' and you don't take it. Another one asks questions and then appears interested in your health and then gives panadol. This makes the patient feel more respected and he is more likely to take the tablet.

Doctors need to hear from Iraqi people about their culture as you can't really know about a different mentality and system. Culture is about religion, background, ethnicity and group, not just about being from Iraq or the Middle East. We acknowledge that in the last ten years there are many professionals understanding these things and this makes it easier to build up trust. Community consultation and community gathering are important – coffee, food and talking – every month a different community could be involved. Community workers could organise it. Health professionals could discuss health information and Iraqis talk about cultural issues and about life in Iraq.

It's important for the doctor to understand the reasons we have come here from Iraq. Having lived the whole of your life like this, then it's difficult to talk about it and so we keep it buried for years and years before we talk about it – maybe up to ten years. In Iraq war, persecution, imprisonment, fear, poverty and whatever happens to you or your family can cause depression, anxiety, fear, anger or stress. But if you want the patient to talk about what happened all the time, then this is hard for the patient as when they remember they are retraumatised. The only reason that a patient would tell the doctor about the trauma is to educate the doctor. Many GPs and psychologists don't understand about post-traumatic stress disorder (PTSD).

Trust is important and you have to convince the patient it is stress that is causing their problem. But it feels disrespectful to call something stress when the cause of the stress is a reality. PTSD might be an illness but you need to build up trust to hear about what is happening in a person's life. Trust is about having the time, the patient knowing the system and the doctor knowing the background. For example, the doctor says 'don't think too much' and 'give up cigarettes'. If a doctor is expecting this to happen then he is asking me not to be Tarik, I would be someone else. It is truly a problem; I can't tell my story if I think you will not respect it. My family is still unsafe in another country.

If you have no idea about what happened in Iraq then you may not believe what the patient says. You can't help without understanding the background. One Iraqi man is still panicky and afraid because one day he saw a police car at the surgery. In Iraq police are there to persecute you, not to protect you. It takes years to understand the system

here. If he sees a police car then he thinks it's looking for him.

Another man was complaining about his sleep and he asked God to help him. The psychologist didn't understand and asked what Allah had to do with this and that this was nothing to do with God. In Muslim culture God is in charge of everything and he makes you well, bad, dictates your future, what sort of family you have, wealth, health, wisdom and even helps you sleep. It is God's will for me to be in Australia, not my choice. God has brought me here.

Someone I know told about their brother who was taken from his house by the police. Eighteen months later the family received a paper saying that he was hanged with no court process. In Australia the police do not do such a thing. This man could feel the pain of his brother. The make-up of the family means that if something happens to an individual then it happens to the whole family. My mother died in Iraq since I have been here. I couldn't really feel that I'm a good son until I went back to Iraq and visited the grave. This is not just something that happens for the nuclear family but also for the whole extended family.

The new life, culture and language in a new country can also cause more stress. In Iraq if someone has cancer then the doctor would tell the family and not the patient, as compared with here you tell the patient and not the family. When someone has an operation you give lots of information about risks and side-effects and the patient has to sign an informed consent. This is very frightening as we don't have anything like this in Iraq and think it will all happen. If you say 'You may die' then the patient thinks you are telling them they will die and why would they have the operation. Trust is very important and we might need to talk to our GP about what the specialist says as we don't know him at all. We have to believe the doctor that what we say is confidential. We worry that if we see a doctor from the same background as us then he will tell others as in Iraq there is no confidentiality.

Doctors need to be loveable and offer friendship. The real treatment is not the tablets, not the psychotherapy, it's friendship. Friendship is about time and personality – how you see the patient as a person, respect them, take them seriously and listen properly. Doctors need to work from their brain and heart and believe their patients. We need to like each other, and then we will both listen.

Many writers have discussed the problems in diagnosing and treating mental illness in patients from other cultures when they come into a Western medical environment.⁴ Up to 60% of those who come to Australia as refugees will have depression, anxiety or

PTSD.⁵ By definition all have had traumatic pasts and have escaped from their own country fearful for their lives. Often after spending many years in a refugee camp they arrive in Australia to face the added problems of settlement in another culture as well as their past grief and trauma.

Refugees will be struggling with many health issues on arrival in Western countries such as Australia and their mental health problems may only surface after the initial 'honeymoon' period. The hopes that life will be better are soon complicated by the many other factors that need to be dealt with. Grief for family, relative poverty, unemployment, different food, isolation and the many other cultural differences can trigger old problems as well as new ones. But in the isolation of a new health culture the patient may not know where to turn, whereas in the past they might have had an extended family, a supportive community and traditional healers.⁶

The definition of mental health problems will be different in every country and culture. Some of this will be about such 'invariables' as tradition and spiritual beliefs but many of the reasons will be 'variables' such as media portrayal of people with mental health problems, lack of mental health facilities or workforce, mental health literacy and stigma. The World Health Organization (WHO) and other bodies are attempting to address these issues with campaigns in many countries.⁷

The belief that mental illness is an intellectual or spiritual problem will also exacerbate the shame of the condition, especially if a person does not recover quickly. It implies that the person is lazy, stupid or not spiritual enough. When someone is depressed or anxious, they are often unable to try harder to overcome their lethargy, struggle to concentrate or belief in the future. This of course makes it even more difficult to see a path to recovery and hence they are more likely to hide how they are feeling.⁸

The issue of human rights and government protection for people with mental illness is also different in each country. For those countries with only a limited mental health budget, people with severe mental illness will sometimes be locked away in very poor conditions. There are still countries in the world, many of them the source countries for our refugee patients, where a diagnosis of mental illness is used for political reasons to incarcerate people. This will add to the fear and stigma of being diagnosed with a mental illness.⁷

The expression of deep feelings and beliefs is very much culturally mediated. They will usually only be accessible in a person's first language and so using an interpreter when dealing with mental health issues is essential.⁹ Even then, many languages do not have words for what Western practitioners might call 'mental health problems', such as depression and

anxiety, or even for mood or feelings. These concepts might be communicated in spiritual terms or using traditional or semi-medical allegories such as 'high' or 'low blood pressure' (anxiety or depression) or 'wind'.^{2,10} When people are struggling with depression or anxiety, or even just with the stress of seeing a health professional, they may lose their ability to express themselves in words. PTSD in particular seems to affect people's ability to learn a new language or even find words in their mother tongue to relay their feelings.

Somatisation is used as a mental health 'diagnosis' in Western cultures but in many cultures might be the only way of expressing psychological distress.¹¹ It might be best to view it as a type of body language or as 'the expression of personal and psychological concerns through somatic means'.¹² The separation of mind and body is a Western phenomenon and when dealing with people from more collectivist cultures this separation will make no sense.

Walking with a patient through the meaning of their symptoms using a series of questions such as that of the *Cultural Awareness Tool* will often reveal the psychological or social distress underlying the physical presentation.¹⁰ It is important then to have a holistic approach and to deal with both the physical and social as well as the psychological problems, rather than just deal with the mental health problem.

For most refugees, coming to a new country involves a lot more than just being grateful to be safe and to have clean water, good food and access to education. The culture shock and even 'continuous traumatic stress disorder' will for some be enormous, and involves things others may take for granted, such as dealing with social security, banks, schools, transport and the health system. On top of this is the grief of losing a country, an extended family, a language, an occupation, food that is familiar and all the little things that unconsciously make each one of us feel at home in a certain culture.¹³ Many people are still living in poverty as they have debts to pay in their country of origin or are supporting family members in another country. Some may feel an overwhelming sense of guilt that they are safe and other members of the family are still living in extreme poverty or in dangerous places.¹⁴

Experiences of torture and trauma in the past mean that people in authority, the police, the army and sometimes health professionals may not be seen as trustworthy as they have been part of the regime that has persecuted the refugee patient. It will take a long time, patience and good relationships to counter these experiences. For young people there is the additional issue of spanning two cultures as they struggle to find a way to socialise with friends, wear different clothes, learn new ideas and deal with

traditional expectations of education, occupation, marriage and children. This will often leave them at odds either with their family or with their new culture.¹⁵

Mental health literacy is a very important part of helping people of refugee background feel confident about the mental health system in the new country. This will not happen immediately, but people will slowly move through the 'stages of change'.¹⁶ Many will be pre-contemplators, having never thought about mental health issues in a Western context before. It is only slowly that they will move through the stages of contemplation and planning until they gain enough understanding, trust and decreased shame to move into the action phase of accepting treatment.

It is important not to stereotype people from a certain religion or culture. Culture encompasses a total way of life – the underlying pattern of thinking, feeling and acting – of particular groups of people.¹⁷ It helps people make sense of their surroundings and includes mostly unconscious attributes such as attitudes, behaviour, assumptions and values.¹⁸ Learning about a patient's belief system shows respect and interest and acknowledges the patient as the expert in their own culture. More than this, however, it ensures that the health professional is not dealing with the patient from the professional's own ethnocentric stance. This is especially important when using psychotherapeutic techniques such as cognitive behavioural therapy, as what is 'good, right, normal, ethical and moral' will be different in every culture.¹⁹

Spirituality is at the centre of the lives of many of our refugee patients in a way that is quite foreign to many Western practitioners. What might look like passive fatalism to some, may also be a deep source of strength, courage and wisdom that has sustained people through the many difficulties they have faced. For some, what they view as inflexible 'rules' of their religion may hinder changes they see as important to settling into their new country. Health professionals who do not consider themselves as religious may not think about asking patients about their religious or spiritual life, or may shy away from treading on this 'holy ground' for fear of offending patients. This puts them at risk of having little access to either a causative factor of psychological distress or to a source of relief from that distress.²⁰ These parameters are likely to be different for every individual and should not be assumed on the basis that someone associates with a particular religion. In all religions there will be those who have only a cultural attachment to their religion, some who seem only to stick to the rules and others who express a deep and sustaining faith.¹⁹

In order for health professionals to gain an increased understanding of a certain culture it is

important for them to be constantly open to what people from that culture have to teach them. This may even involve a designated mentor, such as a community health worker, who can answer questions that it might be inappropriate to ask patients or interpreters. The doctor needs educating about the situation in the country of origin to properly understand and believe what has happened to the patient and so be able to help them. The patient is actually the expert here and may be the only one that can inform the health professional about the situation. Mutual education means that the community develops mental health literacy and trust and health professionals learn cultural awareness. The suggestion that this be organised by community workers in the context of food has been taken up by many organisations. Unfortunately, this does not usually involve doctors, who are renowned for sticking to a biomedical model rather than dealing with a more holistic biopsychosociospiritual model.²¹

A person's world-view will range from that of the individualistic, mostly Western, concept of self and personal responsibility to the collectivist view which is more about family, community, spirituality and consensual decision making and responsibility. For those from a more collectivist background the priorities in a person's life may not be their own success, wellbeing or even safety, but that of their family or community.²² This needs to be respected even if the doctor has little true understanding of the nature of relationships in those with a different view of the world.

Post-traumatic stress disorder (PTSD) is a very common problem in people of refugee background. Its origins lie in a person experiencing an 'extreme traumatic stressor' and a following syndrome of re-experiencing the event, avoiding certain stimuli and physiological and psychological symptoms.¹¹ In diagnosing PTSD, the patient may feel that the doctor is 'explaining away the horror and misery they have experienced to a politically or medically expedient' category.¹⁹ People who come from countries that have been at war or in chaos for many years have sometimes normalised the 'depression, anxiety, fear, anger or stress', as by any measure this is an expected reaction to what they have been through.

It is of the utmost importance to have a collaborative relationship where the doctor listens respectfully and carefully to the patient's story, helps the patient to acknowledge the stress behind their symptomatology and then uses a patient-centred approach to assist the patient to find ways of dealing with their symptoms. Such an approach might be narrative therapy, where the patient's own skills, hopes and resilience are utilised rather than the doctor dictating what would be helpful.²³ The importance of 'telling their story' is different for every

patient. For some, debriefing is a way of acknowledging and clarifying a situation that has been buried for a long time, dealing with the guilt and grief that has gathered there and sharing the burden. For others this process involves reliving the trauma and the patient ends up feeling worse.²⁴

Many doctors complain that an interpreter will speak for several minutes to a patient before asking a question. This is often because it is impolite in many cultures to ask direct questions before building a basis for the relationship. The development of cultural humility, trust, respect and compassion as essential tools when working across cultures were seen as so important to Walker and Barnett in their 58-chapter book *Immigrant Medicine* that they take up much of the first two chapters.²⁵ There is a body of literature on the importance of the doctor as part of the therapy in any encounter.²⁶ In the overwhelming struggle for time-poor GPs to deal with evidence-based medicine this is sometimes forgotten. In refugee health it is likely to be the most important element in patients undergoing their investigations, taking their medications and returning for follow-up.²⁷

The healing power of love, humour and kindness should not be ignored. It is rare for these elements to be added to our evidence base, but for people who have suffered dreadfully at the hands of our fellow human beings these may be rare commodities. Feeling accepted, finding new meaning in life and sharing a common humanity are deep needs in all of us. The ability for patient and doctor to laugh together at a shared joke, to cry together with grief or horror, to look into the past or the future with another human being who is trying to understand – sharing these will take both doctor and patient to new places.

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