Clinical practice in early psychosis

Working with cultural diversity in early psychosis

Introduction

Cultural diversity is a fundamental feature of the Australian population. In 2011, it was reported that almost a quarter (24.6%) of Australia's population was born overseas.[1] The American Psychiatric Association states that 'Culture refers to systems of knowledge, concepts, rules, practices that are learned and transmitted across generations … includes language, religion and spirituality, family structures, life-cycle stages, ceremonial rituals, and customs, as well as moral and legal systems.'[2]

Culture influences our values, beliefs and behaviour around health, wellbeing and treatment. It is a particularly important factor in the way we view mental ill-health and our attitudes towards help-seeking following an episode of illness. Culture is not static and encompasses a number of different variables that affect how we as individuals experience the world.[3] Traditionally, cultural diversity was mainly referred to as culturally and linguistically diverse (CALD) but recently there has been a shift towards talking about 'diversity' as a whole and the different types of cultures that young people themselves identify with. For example, a young person who is Greek, lives in inner urban Melbourne, is a street artist and has sexuality issues may identify more with being an artist and being part of the lesbian, gay, bisexual, transgender and intersex (LGBTI) community than their Greek heritage. It is important to be aware that this young person's identity is likely to change during the course of their development as they become an adult. Therefore, the way society views cultural diversity needs to change to catch up with the new generation and their way of thinking about their diverse identities.

Cultural diversity can include Aboriginal and Torres Strait Islander young people, young people from LGBTI communities, refugees and asylum seekers and homeless young people. For the purposes of this clinical practice point we are going to use the term 'culturally diverse' or 'CALD' and focus on CALD communities specifically in the context of early psychosis.

Working with CALD communities is essential because these communities have lower rates of accessing community services than the general populations and when CALD young people do access services they often present in a crisis and are admitted to inpatient care.[4] It is essential that youth mental health services develop culturally responsive care that appropriately assesses, engages, diagnoses and treats CALD young people and their families to help them return to their normal developmental trajectories.

This clinical practice point is designed to help clinicians:

- understand the importance of working with CALD young people and their families
- develop effective ways of working with CALD families
- learn how to explore cultural explanatory models of illness
- develop ways of effectively working with interpreters.

> **❝ ... inequities are never the result of single, distinct factors. Rather, they are the outcomes of intersections of different social locations, power relations and experiences.[5]**

Why is working in a culturally diverse way important in early psychosis?

There are a number of environmental risk factors known to increase the risk of experiencing mental ill-health that are more common in CALD communities within Australia and include:[4]

- social disadvantage
- unemployment
- separation from families and communities.

Refugee young people are a group at high risk for mental ill-health because of their increased exposure to trauma, forced migration and settlement-associated stressors.[6] In Australia, refugee children and young people have low use of mental health services despite having relatively high prevalence of mental ill-health.[4] Young people from CALD backgrounds who do access mental health services do so at a later age, when illness is more severe and more likely to be admitted to inpatient care with treatment for a longer time.[7] Data from the Victorian Transcultural Mental Health (formerly known as the Victorian Transcultural Psychiatry Unit) shows that people from CALD backgrounds have consistently lower rates of access to mental health services (compared with the general population) but have higher rates of involuntary admission and a higher proportion are diagnosed with psychosis.[8] The lower rates of access to mental health services seen among CALD communities could be attributed to:[4]

- cultural and language barriers
- stigma associated with mental ill-health.

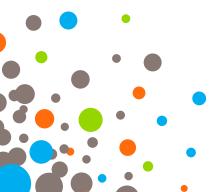## Challenges for CALD communities upon migration and settlement

There are number of challenges young people and families face following migration and settlement:[4]

- adapting to a new culture and language (also known as acculturation)
- negotiating issues of belonging and identity
- experiencing racism and discrimination
- becoming familiar with Australian's social systems (e.g. political systems and social rules).

When people migrate from one country (culture), usually their country of origin, to another country (culture), often referred to as the host culture, they undergo a process of acculturation.[9] This process of moving from one country to another requires individuals to adapt to the new country's (culture's) appropriate behaviours, values, custom and language. The word acculturation describes an individuals' psychological change during this process of adapting and transitioning between two cultures.[9] Refugee young people may have transitioned to more than one culture prior to arriving to Australia which means that they have undergone multiple cultural transitions prior to settling in Australia.

There are four types of acculturation strategies: assimilation, integration, marginalisation and separation.[10] Different family members may adapt different acculturation styles, which can create conflict within a family. This is especially important during adolescence and early adulthood when young people are differentiating from their parents and forming their own identity. This developmental stage is marked by strong influences by peers which may be more in line with the desire to belong to the host society.

The acculturation strategy a young person adopts depends on the values they place in them participating within the host culture, including forming relationships with Australian people, and how important they value maintaining their own cultural heritage. If a young person believes it is important to become Australian and leave their cultural heritage behind – they will adopt an assimilation strategy. However, if a young person believes that it is important to develop relationships with Australians and become socially competent in the new culture but that it is equally important to maintain one's own cultural background, they will then develop an integration strategy.

It is important for clinicians to be aware of differences in acculturation types because they are linked with psychological wellbeing. Separation and marginalisation are often associated with poorer psychological outcomes, which can cause stress, social and mental health issues.[11] Separation involves the young person interacting only with their own cultural group, helping maintain their language and customs, but not allowing them to develop sociocultural competence in their host culture. Marginalisation occurs when the young person decides to let go of their cultural heritage but do not adapt to their new culture.

> ❝ I guess there's two things in having a mental illness, the first one is that mental illnesses usually come with judgement and number two is cultural judgement. In Colombia, in my case, apart from, you know, having a mental illness … my mum would say "You just need to go to church. That's what you need." It was really, really hard because I knew my mum was not going to understand.

Young person,
Platform participant, Orygen Youth Health Clinical Program

Challenges in diagnosis across cultures

Young people from CALD backgrounds have lower rates of access to mental health services and often present in a crisis. A crisis is often a traumatic experience for both the young person and family, and is accompanied by distressing symptoms. Data has consistently demonstrated that young people from CALD backgrounds are often admitted to inpatient care on an involuntary basis which makes engagement and treatment challenging.[4] Some may not be fluent in English, and may require an interpreter, which increases the confusion they might be experiencing during the crisis.

> ❝ It's lonely and confusing … very confusing for families. And having a young person with a mental illness, it puts you into the mental health system which is terrifying even if you've grown up here. It's incredibly terrifying when you don't understand what people are saying … when you don't understand how the system works.

Family peer support worker,
EPPIC, Orygen Youth Health Clinical Program

Strategies for working with cultural diversity in early psychosis

There are many strategies clinicians can use to work successfully with cultural diversity. Clinicians need to build a strong rapport with young people and their families to work effectively with cultural diversity in early psychosis. This includes clinicians needing to understand:

- cultural background
- religion
- languages spoken at home
- social formalities.

Clinicians need to respect different cultural differences and beliefs to help engage young people and their families. Respecting cultural beliefs helps to facilitate communication with families and obtain collateral information for a thorough assessment and accurate diagnosis. It is important for clinicians to seek information about language and cultural norms from 'cultural exports' such as religious or community leaders. Having a 'directory' of community leaders in the service's catchment area can help clinicians collaborate with CALD communities to help understand pertinent aspects to the young person's cultural presentation and how this differ from the rest of the community.

Partnering and collaborating with organisations that provide services for CALD communities, such as migrant resource centres, is another way clinicians can help facilitate engagement into the service and improve access rates of young people with CALD backgrounds. This can subsequently provide clinicians with a culturally responsive framework to help them tailor treatment and care for CALD young people and their families. Box 1 lists useful organisations clinicians can use to work with CALD young people.

> **Box 1. Organisations clinicians can use when working with cultural diverse young people**
>
> Mental Health in Multicultural Australia
> http://www.mhima.org.au/
>
> Victorian Transcultural Mental Health
> http://www.vtmh.org.au/
>
> Foundation House
> http://www.foundationhouse.org.au/
>
> Transcultural Mental Health Centre NSW
> http://www.dhi.health.nsw.gov.au/tmhc/default.aspx
>
> Queensland Transcultural Mental Health Centre
> https://www.health.qld.gov.au/metrosouthmentalhealth/qtmhc/
>
> Survivors of Torture and Trauma Assistance and Rehabilitation Service (STTARS)
> http://www.sttars.org.au/
>
> Western Australian Association for Mental Health
> https://waamh.org.au/
>
> Migrant resource centres across Australia

Engage CALD families

Language and cultural differences can have a significant impact on the ability of clinicians to work effectively with families. These should not necessarily be seen as a 'challenge' but something clinicians should be mindful of, particularly where English is not their first language. Clinicians need to understand the expected roles of individuals within the family. For example, if a young person is the eldest son in a family, they might have family expectations such as helping the family attend medical or Centrelink appointments, or helping young siblings with their homework as the parents are not fluent in English. These role expectations may increase the stress for the young person during the

early recovery phase of psychosis. It is important that clinicians work with the family to develop alternative strategies to support the family during this time.

Clinicians need to be aware that there may be differences in acculturation strategies between young people and their families that may cause value and belief clashes. For example, if a young person has adopted an assimilation strategy, by adopting the values and attitudes of the host culture, and their parents have adopted a separation strategy to hold onto their heritage and beliefs. This can cause conflict within the family and increase stressors at home which can affect the young person's recovery.

Clinicians should also consider the following when working with CALD families:

- differences in values, attitudes and explanatory models
- psychoeducation and how this can be tailored to provide culturally responsive care
- stigma associated with mental ill-health in different cultures
- confidentiality and how to discuss this
- using telephone versus face-to-face interpreters
- duration of sessions (especially when working with interpreters)
- factsheets from multicultural organisations to provide information on psychosis and other mental health disorders.

Treatment and care should be tailored to the beliefs system of the family to help the young person return to their premorbid functioning.

> " I think people really appreciate when you do to try and understand what their culture is and what they're coming from. I guess, some of the things I've picked up is there's so much stigma, I think that would be one of the really big things. I think for a lot of families, they don't have any other supports.

Family peer support worker,
EPPIC, Orygen Youth Health Clinical Program

Work effectively with interpreters

Clinicians should always use a professional accredited interpreter when working with young people and families if English is not their first language – when conducting an assessment and for the duration of the care with the service.[12] For example, a young person may have limited English fluency – they can understand basic concepts and can communicate simple information but are unable to understand complex information. So the young person might be able to understand some of the clinician's questions and respond using basic English but will have difficulties communicating details of their symptoms, their experience of psychosis, possible side effects and how they are feeling. Effective communication is achieved by working effectively with interpreters. This avoids misdiagnosis and ensures that the appropriate interventions are tailored to the young person and their family's unique needs.

It is important to work with interpreter as ally in treatment – clinicians should brief them about the purpose and aims of the interview before the meeting to ensure that everyone is on the same page. It is always important to check whether certain medical or psychiatric terms are difficult to translate because certain terms such as depression or psychosis do not have direct translation in many languages. As the interpreter is part of the interview process, it's important to debrief with them following a difficult session.

It is important to remember that in small emerging communities, such as recent migrants to Australia, there may not be an accredited interpreter. In these cases, it may be appropriate to use a non-accredited interpreter depending on whether the young person and the family know the interpreter personally. It is essential for the young person, the family and the interpreter to all agree to proceed with the interview to make sure they feel comfortable and safe disclosing sensitive information.

It is also necessary to consider whether the young person and their family has experienced persecution in their country of origin and whether they are reluctant to work with an interpreter of the same country. In these instances, it may be appropriate to book an interpreter who speaks the same language from a different country to make sure the young person and their family feel comfortable disclosing person information.

> **TIP** It is always important to ensure that the young person and the family don't know the interpreter personally. If they do know the interpreter, keep on asking whether they feel comfortable completing the interview. The stigma of mental ill-health in culturally diverse communities affects how much information is being communicated during the session.

Use a cultural formulation-based approach

Clinicians should use a formulation-based approach that incorporates the cultural presentation of young people and their families when working with CALD young people entering an early psychosis service. Using this approach will help the clinician explore a common language between the young person, family and themselves to ensure that everyone is working towards the same recovery goals.

❝ We used interpreters when I was at the IPU. But there's this slang between every language, so Chileans and Colombians we speak very differently. I remember in my case, my interpreter was Chilean and there were things that just didn't go through the way they were supposed to. I remember interrupting the interpreter and to tell him that's not what she meant really.

Young person,
Platform participant, Orygen Youth Health Clinical Program

Kleinman's six step approach towards cultural formulation

Kleinman developed a simple six-step approach towards explanatory models and cultural formulation.[3] This approach aims to help clinicians encapsulate what's important for the young person and their family based on their values and beliefs. Below is an adaption based on Kleinman's six-step approach.

Step 1. Ask young people what they identify with.

Do they identify with a certain ethnic identity? Ask young people how they describe themselves to determine whether culture is an important part of their sense of self. This focuses on what they consider to be important and relevant to their everyday lives. This will of course vary from person-to-person even if they are from the same ethnic community. Asking young people this will provide clinicians with information about how the young person sees:

• themselves
• their place within their family
• their social network
• society.

Clinicians should also ask young people what part of their cultural identity will make the problem worse or better. This will help determine whether social discrimination (due to migration), racism (due to ethnicity) or sexual orientation will influence their treatment and recovery. Helpful questions to guide clinicians assess identity can be found in the 'Cultural formulation interview' in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) under the section entitled 'Role of cultural identity'.

Step 2. Ask young people what is at stake if they experience an episode of psychosis.

Ask young people and their families what effect an episode of psychosis will have on them and their lives. This step is related to the young person's adaptation to psychosis and how they view their recovery, which also incorporates significant cultural themes.

Step 3. Allow young people to explore their illness narrative.

During this step, clinicians are encouraged to ask a series of questions to help understand the meaning of psychosis from the young person's perspective. Ask young people a few questions to help them explore their narrative, such as:

• What do you call this problem?
• What do you believe caused this problem?
• What course do you expect it to take?
• What do you think this problem does to your body?
• How does it affect your body and your mind?
• What do you fear the most about this problem?
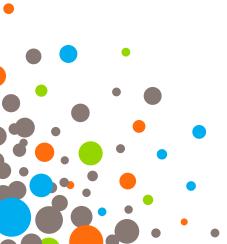• What do you fear most about treatment?

This will help clinicians understand their explanatory model of illness and in turn help clinicians tailor interventions to match their illness narrative. Clinicians should use the language the young person uses to describe their illness, for example, if they believe that their symptoms are caused by an 'evil eye' use this terminology.

Step 4. Ask young people about their psychosocial stressors.

This step is used to help clinicians understand the young person's ongoing psychosocial stressors in their life that may exacerbate their psychotic symptoms. This is related to the stress–vulnerability model by trying to find cultural factors that will mitigate stress and help the young person's recovery. Clinicians should ask young people about:

• family tensions (including value clashes)
• changes in roles within the family
• changes in relationships and friendships
• work or school difficulties
• financial issues
• personal difficulties adapting to psychosis.

This information can be used as targets for specific interventions to help reduce overall stress and help the young person work towards functional recovery.

Step 5. Consider whether culture influences the young person's relationship with their treatment team.

Clinicians should carefully examine whether culture influences the way young people interact with them. Mental health professionals and their views are based mainly on biomedicine and a Western approach towards treatment. This can have a significant impact on the therapeutic relationship with a young person who may have a significantly different view towards illness causation and its treatment.

It is important that clinicians do not stereotype young people and families from CALD communities and to understand them as individuals.[3] This can help build a trusting therapeutic relationship which is essential for engagement and subsequently improved mental health outcomes.

Step 6. Disadvantages of a cultural competency approach

Clinicians should consider whether interventions are effective for the unique cultural presentation of each young person and their family. After having considered the cultural barriers to engagement and treatment, clinicians should ask themselves 'Is this going to work with this young person and their family?'

It is also important to remember that within mental health settings, there may be complex presentations regardless of cultural backgrounds. This means that there may not be an easy resolution to complex presentations even when addressing all inherent cultural factors.

DSM-5's cultural formulation interview tool

The DSM-5 has developed a cultural formulation interview to help clinicians when assessing culturally diverse people to inform diagnosis and intervention planning.[13] The cultural formulation interview has four domains:

- cultural definition of the problem
- cultural perceptions of cause, context and support
- cultural factors that affect self-coping and past help-seeking
- cultural factors that affect current help-seeking.

Each of these domains have interview questions that help facilitate a person's own narrative of their illness, help the clinician understand what their social support system is like, and engage people and their support system in the treatment process.[13] For more information please see 'Cultural formulation' in the DSM-5.[2]

> **TIP** There are certain cultural domains of a young person's presentation that can be applied to many sections of the cultural formulation. Clinicians should ensure that the young person's cultural formulation is as comprehensive as possible and remember that biopsychosocial aspects of their presentation will coexist in various domains. It is the same for cultural formulation – there will be an overlap of information in more than one cultural domain. It doesn't matter whether information is repeated in more than one cultural domain, as long as the information is captured and informs interventions.

Common question about cultural formulation

Q: how do we differentiate a normative cultural presentation from psychopathology?

It is important for clinicians to gather information from family, friends and community leaders about what they think has caused the problem to help differentiate what is a normal cultural presentation from psychopathology. For example, it is not uncommon for certain cultures to believe that a deceased loved one will speak to them for a period of time following their death, before transitioning to the afterlife. The question is how does the young person's presentation deviate from their community cultural norm in terms of frequency, intensity, duration and distress? Clinicians may find out that it is normal for that culture to grieve and hear the voice of a dead person for 3 months and not cause them distress because it is comforting and allows the person to say goodbye, then the voice eventually disappears.

Explore explanatory model of illness of young person and their family

Explanatory models of illness refers to a set of ideas about an episode of illness that attempts to answer questions about:[14]

- cause of illness
- time and onset of illness
- nature of the illness
- severity and course of the illness
- treatment of illness.

Explanatory models of illness attempts to distinguish between the illness or disorder (e.g. early psychosis) and the individual's experience of the illness (e.g. malevolent spirit possession). This illness experience provides meaning to the young person and their family that is non-stigmatising in their attempts to

make sense of the distressing symptoms. Helping young people and families explore their explanatory models of illness assists clinicians in understanding the meaning the illness has to them. Clinicians should elicit the young person's explanatory models of illness because it contains the young person and family's ideas about appropriate treatment (e.g. spells or rituals). This information can help clinicians engage young people and their families and can guide help-seeking behaviour. Therefore it is important for clinicians to routinely use exploratory questions to elicit explanatory models of illness from young people and their families they are working with.

Use a strengths-based approach

A strengths-based approach emphasises the resilience of young people rather than focusing on challenges and limitations. Focusing on a young person's strengths will empower them to manage their own wellbeing. For example, refugee young people and their families have incredible resilience despite often having traumatic pre-migration experiences because of war, violence, deprivation and loss. Encouraging discussions about friendships, family, achievements and their overall resilience in the face of adversity can help the clinician and young person identify strengths and hence potential protective factors.

Some questions clinicians can ask themselves are:

- What are the strengths for this young person and their family?
- What are the young person's current coping strategies? How can we help them improve these coping strategies? What new coping strategies can they learn?
- What supports does the young person have within their family, social network and community?
- How can I involve the young person in problem-solving and decision making around treatment decisions? Please see the resource entitled *Clinical practice in youth mental health: shared decision making* for more information.

Negotiating a shared understanding: finding common ground for treatment

Clinicians should always try to find a common ground for treatment when working with young people and families from culturally diverse backgrounds. This means negotiating their worldviews between the explanatory models of the young person and their family and the Western biomedical approach to treatment. Figure 1 represents a way of negotiating worldviews.

Negotiating a shared understanding for treatment is finding that common ground between worldviews and is an important strategy clinicians can use. Clinicians should identify a common denominator regardless of the inherent differences in worldwide, while respecting the cultural beliefs and values of young people and their families. The overall aim is for the psychotic symptoms to improve so that young people can make gradual functional gains to return their premorbid developmental trajectory. In an early psychosis service, common ground can be when the young person and the clinician agree to identified treatment goals regardless of differences within their explanatory model of illness.

For example, a young person's main goal may be to reduce the symptoms of auditory hallucinations so that they are able to go back to university. The common ground here is that both the young person and the clinician want to reduce the auditory hallucinations regardless of whether the symptoms are cause by a 'malevolent spirit' or by a chemical imbalance in the brain requiring antipsychotic medication. The clinician negotiates treatment with the young person and their family to find a common ground that is shared between the young person and the clinician (see case scenario 'Maria').

It is important to incorporate the culture and values of the young person and their family into the treatment plan and negotiate how best to work with each other. This will help clinicians effectively engage CALD young people and families, incorporate their cultural values and identities, using a shared-decision making approach, into treatment decisions, to help them work towards their recovery goals. Some useful tips for working with CALD young people are presented in Box 2.
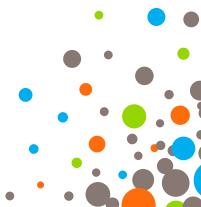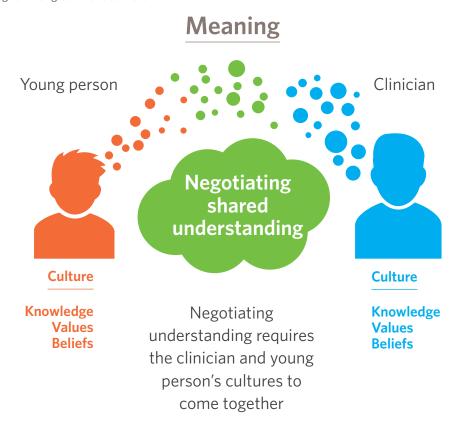
Figure 1. Finding common ground for treatment

Meaning

Young person   Clinician

Negotiating shared understanding

Culture

**Knowledge
Values
Beliefs**

Culture

**Knowledge
Values
Beliefs**

Negotiating understanding requires the clinician and young person's cultures to come together

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Box 2. Tips for working with CALD young people

- Don't stereotype – cultures are made up of individuals and there will always be variation
- Explore each young person and their unique characteristics, including acculturation strategy
- Explore the values of the young person and their family to modify interventions to fit their cultural norms
- Explore clashes in values and beliefs that may exist between the young person and their family
- Explore cultural family norms, gender roles and social structures – it is important to find out who is the head of the family, often it is the father or the eldest male who assumes responsibility for the family
- Don't impose your own explanatory model of illness – this can cause disengagement and non-adherence with treatment
- Always obtain collateral information from family members, peers and community leaders to help with clinical understanding

- Always complete a thorough mental state examination, using appropriately accredited interpreters where possible
- Always try to book the same interpreter for continuity
- Always communicate using plain language
- Avoid using jargon when communicating
- Explore any links between their illness experiences and their cultural framework
- Always negotiate treatment regardless of differences in worldviews between explanatory models
- Find common ground with young people to identify shared treatment goals to help them return to their premorbid developmental trajectory
- Help young people engage in shared decision making about treatment and identified goals incorporating culturally responsive care

Case study: Maria

Maria is a 23-year-old Italian female who moved to Australia 3 years ago, to study at University. She migrated from a small village in the south of Italy, her three brothers were murdered by the mafia 4 years ago. Her parents raised money to help her move to Australia as they were concerned for her life. As Maria is the only daughter, her family expect her to send money back home.

Initially, Maria went to a GP who diagnosed her with an anxiety disorder and referred her to a youth mental health service. She didn't attend the service because her mother said she had been cast the 'evil eye'. Maria followed her mother's evil eye treatment recommendations, including going to church to pray twice a week, lighting three candles for each of her dead brothers and wearing an amulet sent from Italy with special powers.

Maria's mental state significantly deteriorated over the next 3 months and her colleagues were concerned because she started talking to herself. Maria was referred to an early psychosis service where she disclosed she was hearing voices of her dead brothers saying that she had the evil eye and that her life was in danger. During the assessment she explained she had started carving an eye on the palm of her hand with a knife, in an attempt to deflect the evil eye. Due to her risk to self, distressing psychotic symptoms and PTSD, she was admitted into the adolescent inpatient unit.

The inpatient treating team worked in a culturally sensitive manner by respecting Maria's worldview when taking steps to negotiate treatment by finding common ground. This included:

- Respecting her belief that someone had cast the evil eye.

- Exploring what she thought would help with the evil eye, because the voices were causing distress and triggering past traumatic content.
- Searching for an Italian priest to dispel the evil eye.
- Exploring what was most important for her recovery which included 'to reduce the voices in my head so I am no longer haunted by memories of my brothers' murders so I can return to work and send money to my parents'.
- Suggesting a trial of medication that help reduce the powers of the evil eye that could be easily combined with the treatment of the holy water and the Italian priest.
- Managing Maria's concerns about her distress from symptoms and poor sleep by using medical treatment such as antipsychotic medication.
- Finding an Italian priest and making arrangements for Maria to attend church to pray and perform rituals with the holy water.

The treatment team was able to find common ground and negotiate a combined treatment approach between Maria's explanatory model and the biomedical model. Maria reported that the voices had reduced to whispers and that she was no longer experiencing intrusive memories of her brothers and their murders. She returned to her normal sleeping patterns and said she felt ready to return to her part-time job.

❝ Cultural sensitive practice does not mean offering only non-Western treatment to young people experiencing an episode of psychosis. It requires clinicians to elicit a young person's experience of their illness from a culturally sensitive position to find common ground to begin a process of negotiating treatment to combine both Western and non-Western treatments.'

Senior clinician,
EPPIC, Orygen Youth Health Clinical Program

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Acknowledgements

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