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Whose Reality is it Anyways? Working with Alternate Experiences.

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Objectives

1. To reduce stigma by learning about common conceptions and truths about psychosis.
2. To redefine psychosis as “alternate experiences” that have meaning. By doing so, you will be able to describe the importance of creating relationships with these “experiences”.
3. To identify and explain at least three interventions to support someone experiencing an “alternate experience”.

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Common Conceptions



Only powerful
medications can stop
someone from hearing
voices.

Common Conceptions activity credit given to Western Mass Recovery Learning Community (2019)

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Role of Medications

Antipsychotics may reduce, quiet, or stop voices
AND
there are also many other strategies to manage voices.

Common Conceptions



I believe that those who
hear voices must do
what the voices tell them
to do.

A Word about Stigma

Many people suffer from mental illness and don't "act" on
symptoms.

Not all voice hearers experience "command hallucinations"

Common Conceptions



People who hear voices
understand that this is
what's happening.

Anosognosia

- According to NAMI, Anosognosia is an impaired awareness of one's illness, caused by damage to specific parts of the brain (<https://www.nami.org/About-Mental-Illness/Common-with-Mental-Illness/Anosognosia>)
 - When the frontal lobe isn't fully operating, organizing new information and developing a revised narrative becomes difficult.
 - Most often seen in people with schizophrenia and bipolar disorder (as well as diseases like dementia).
- From the Greek meaning "to not know a disease"

Anosognosia continued

- Can make treatment more difficult, leading to conflict with others if not understood.
- Common reason for stopping medications and avoiding treatment.
- Typical to have variations in awareness.
- Anosognosia is NOT the same thing as denial.

Common Conceptions

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If someone hears voices,
they must have a
diagnosis of
schizophrenia.

Reasons Why

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- **Mental illness**
 - According to the Cleveland Clinic (2022), approximately
 - 75% of people with schizophrenia experience auditory hallucinations
 - 20-50% with bipolar; 40% with PTSD; 14% with an anxiety disorder; 10% with major depression
- Sleep deprivation
- Substance use
- Hearing impairments
- Neurological conditions

Auditory Hallucinations (June 10, 2022), Cleveland Clinic. <https://my.clevelandclinic.org/health/symptoms/23233-auditory-hallucinations>

Common Conceptions

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For some people, their voice hearing
experiences are related to angels, past
lives, chakra opening ancestral
communications and other spiritual
factors.

The Role of Spirituality

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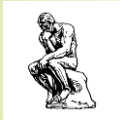
Voice hearers may:

- have experiences that reflect attributes of present or past relationships.
- understand their voices in spiritual or religious terms.
- find spirituality comforting in addressing distressing voices.

Voices and Spirituality (n.d.). Understanding Voices. Retrieved July 26, 2021, from <https://understandingvoices.com/exploring-voices/voices-and-spirituality/>

Common Conceptions

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I believe that voice hearers
can negotiate the
relationships they have
with their voices.

Owning Our Experiences

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We can learn to navigate and own our
experiences and/or responses to them.

Common Conceptions

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I believe there are some cultures where it would NOT be unusual or undesirable to hear voices.

Voices Shaped by Culture

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- Stanford research by anthropologist Tanya Luhmann found:
 - Voice-hearing experiences are influenced by one's social and cultural environment.
 - Among cultures sampled, there were similarities of reporting good and bad voices.
 - Experienced differently! African and Indian cultures described as predominantly positive and more comfortable interpreting their voices. In the United States, viewed as an intrusion and "sick condition". (Parker, 2014)

Common Conceptions


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I believe that there are many famous people who have voice hearing experiences.

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Notable People who Identify with having "Alternate Experiences"




Lionel Aldridge¹
Professional Football Player
Age of Diagnosis: 33




Zelda Fitzgerald²
(1900-1948)
Wife of Walter F. Scott
Fitzgerald and Writer,
Dancer, Artist
Age of Diagnosis: 30




John Forbes³ Nash Jr.
(1928 - 2015)
American Mathematician
Age of Diagnosis: 31



Mary Todd Lincoln⁴
(1818 - 1882)
Wife of Abraham Lincoln
and First Lady of the
United State
Age of Diagnosis:
Unknown



Jack Kerouac⁵ (1922-1969)
Novelist and Poet
Age of Diagnosis: 21




Eduard Einstein⁶
(1910-1965)
Son of Albert Einstein
Age of Diagnosis: 20


¹Lionel Aldridge, Proctor.com. <https://www.proctor.com/blogs/chief-chef-aldridge>
²Zelda Fitzgerald: Beneath the Glistening Surface, i-gargo.com. <https://www.i-gargo.com/blogs/zelda-fitzgerald-beneath-the-glistening-surface/>
³John Forbes Nash Jr. Wikipedia. https://en.wikipedia.org/wiki/John_Forbes_Nash_Jr.
⁴Mary Todd Lincoln, Wikipedia. https://en.wikipedia.org/wiki/Mary_Todd_Lincoln
⁵Jack Kerouac, 20th. <https://www.20thcenturyfifties.com/jack-kerouac/>
⁶Eduard Einstein, Geni.com. <https://www.geni.com/people/Eduard-Einstein/6000000000000000000>

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Notable People who Identify with having "Alternate Experiences"




Vincent van Gogh¹
(1853 - 1890)Artist
Age of Diagnosis: Unknown




Brian Wilson² (1942 -)
Musician and Member of the
Beach Boys
Age of Diagnosis: In His 30's




Ingo Schwichtenberg³
(1965-1995)
Drummer
Age of Diagnosis: Unknown



Peter Green⁴
(1946 - 2020)
Guitarist and Founder
of Fleetwood Mac
Age of Diagnosis: 31



Darrell Hammond⁵
(1955 -)
Comedian and Saturday
Night Live Actor
Age of Diagnosis: During
Childhood



Rufus May⁶ (1968 -)
Clinical Psychologist
Age of Diagnosis: 18


¹Vincent van Gogh, Britannica.com. <https://www.britannica.com/biography/Vincent-van-Gogh>
²As listed: conversation with Bruce Springsteen at The Beach Boys, Official Website. <https://www.thebeachboys.com/brian-wilson-interview-2009>
³Michael Eugene Jennings Schwichtenberg. <https://www.michaeljennings.com/2013/02/20/michael-jennings-schwichtenberg-2013/>
⁴Peter Green, Wikipedia. https://en.wikipedia.org/wiki/Peter_Green
⁵Darrell Hammond, IMDb.com. https://www.imdb.com/name/nm0358887/?ref_=nm_ov_afm_0
⁶Rufus May, Living Mindfully with Violence, substance.com. <https://www.substance.com/2012/03/20/living-mindfully-with-violence-03-20-2012/>

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Defining Psychosis

According to the National Institute of Mental Health, psychosis is defined as: "conditions that affect the mind, where there has been some loss of contact with reality. When someone becomes ill in this way it is called a psychotic episode. During a period of psychosis, a person's thoughts and perceptions are disturbed and the individual may have difficulty understanding what is real and what is not. Symptoms of psychosis include delusions (false beliefs) and hallucinations (seeing or hearing things that others do not see or hear). Other symptoms include incoherent or nonsense speech, and behavior that is inappropriate for the situation. A person in a psychotic episode may also experience depression, anxiety, sleep problems, social withdrawal, lack of motivation, and difficulty functioning overall."

What is psychosis? (n.d.). National Institute of Mental Health. Retrieved July 19, 2021, from <https://www.nimh.nih.gov/health/topics/schizophrenia/raise/what-is-psychosis>



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Redefining as an Alternate Experience

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What is an Alternate Experience?

- Any experience someone has when they hear, see, or sense something someone around them doesn't.
 - These experiences can include all five senses: hearing, sight, smell, taste and touch.
- For some, this experience can be reassuring, for others, it can be confusing or frightening and cause distress.
 - Usually when the experiences are new altogether, the person can be overwhelmed






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Hearing Voices

- Voices can vary in intensity and volume: shouting, whispers, clear or muffled.
- They can speak in sentences or say single words.
- The voices can be male, female, old or young.
- Sometimes they have names but not always.
- People can hear other types of sounds like knocking, crying or music.



Seeing Visions

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- Some people see things that others don't.
- These visions can be very clear and realistic, but they also can be fuzzy shapes, shadows and beams of light .
- Sometimes, it can seem as if people or objects around you are changing shapes.
- As with voices, these visions can be reassuring, funny, frightening or distracting .



Smelling

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- People can smell things that remind them of their past.
 - This can be something nice, like a favorite food or a friend's perfume.
 - Sometimes it can remind someone of a traumatic experience, like smelling smoke when anxious, reminding someone of a fire that burned down their house when they were younger, which could be frightening.
- Sometimes the smell won't be linked to a memory but still be distressing.



Taste

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- This experience is particularly difficult because you can't know if you are tasting something others can't.
- Some people can get a strong bitter taste in their food or drink and can start worrying that there is something wrong with it.
- Others may taste things when they are not eating or drinking.
- They can taste something pleasant (like chocolate or their favorite food) or something they dislike (something bitter).



Touch

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- People can feel something on their skin that isn't there.
- They can feel something crawling on them or something tickling them.
- Some can feel something under their skin which can lead them to feeling uneasy about their body.
- Understandably these experiences can be very confusing and frightening.
- Or someone can feel reassured by a comforting hand on their shoulder.



Any Combination


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- While many may experience one of these senses, many have a combination.
- They could have a strange taste before seeing a vision or feel and see something on their skin that isn't there.

The Alternate Experience

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- These are only a sample of the wide range of what some might experience.
- Remember, for the person experiencing these voices or visions they can be negative, positive, or anywhere in between.
- Remaining calm in the moment and showing interest in what the individual is going through is a good way to support that person in the moment.



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"A Little Insight"



LondonFVN. (2013, July 10). A Little Insight – Young People who Hear Voices. [Video]. YouTube.
<https://www.youtube.com/watch?v=U7jps2r15E>




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Helpful Interventions

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General Strategies


- Acceptance: Acknowledging that the experience is REAL and meaningful
 - Positive self-talk ("I got this" or "I'm okay")
- Relaxation exercises to decrease stimulation

"Steady medication regimen, mindfulness exercises, breathing exercises." – anonymous participant
- Not feeling obligated to do what voices tell you to do
 - Pay as little attention as possible
 - Shift attention (to something enjoyable, funny, entertaining)
 - Problem solving





General Strategies continued

- Exercise to increase stimulation or address negative symptoms
"Exercise, grounding techniques, music," – anonymous participant
- Talking with people:
 - Particularly those who have similar experiences and who have learned to manage and integrate it
 - In a safe (judgement free, non fear-based, non-pathologizing) place
 - Initiating conversation with people about another topic altogether
 - Seeking out the opinions of others you trust (sometimes referred to as "reality testing")



Whose Reality?



- A word on reality testing
 - Language matters!
 - If a participant refers to the strategy as such, use the terminology.
 - If they do not, stay away from this term!
 - It implies that **they** are not in reality and **we** are.
 - Power differential ("my way is the right way")
 - When we try to "challenge" someone's experience that **IS** their reality, it can lead to confusion and frustration, that may have a negative impact on the therapeutic relationship (i.e. mistrust, guarded, avoidance or rejection of treatment, etc.)

"To be honest I don't have a good strategy for managing alternate experiences. Every time I have to open a car door I find it impossible to tell whether I hit another car or not. Also, I frequently worry about knocking someone over in the hallway. Sometimes I can turn to other people for feedback but this has limited usefulness." – anonymous participant



Relationships with Voices

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Creating a Relationship with our Voices

- Talking back to the voices
- Making appointments with the voices
- Compromising with the voices (Half-way attempts to comply)
- Attending to the voices (What are they asking for and why)
- Standing up to your voices (if not comfortable, not feeling obligated to do what your voices tell you)

Supporting the Relationship (Aka Voice Mapping)

- Asking Questions:
 - How many voices do you hear?
 - What do your voices say?
 - Are they present when you feel certain emotions?
 - Are you able to converse with your voices?
 - Who or what do YOU think your voices might be?
 - Is there a time of day you might hear your voices more?

Voice Mapping continued

- Asking Questions:
 - How old does the voice sound?
 - Is there a particular gender?
 - How does the voice speak to you (yelling, whisper)?
 - What are their values?
 - When did the voice first speak to you?
 - What was happening in your life at that time?
 - What could be significant life events?

Good for clinician or participant (client)

Owning your Voices

- Once we have learned to navigate our experiences and create a relationship with them we learn to manage and deal with them
- When this happens:

They are ready to OWN their experiences!!

Helpful Interventions continued

LEAP

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Listen-Empathize-Agree-Partner (LEAP)

Developed by Dr. Xavier Amador, **LEAP** is a helpful method of communication, even when someone has anosognosia. In this instance, set aside any goals of helping someone to accept they might have an illness and focus on staying in the conversation!

Amador, X. (2020). *I Am Not Sick, I Don't Need Help! How to Help Someone Accept Treatment - 20th Anniversary Edition* (20th Anniversary Edition). Vida Press.

The "LEAP" Method

Listen

- Reflective listening without commenting, disagreeing, or arguing.
- After you think you understand, reflect back in your own words your understanding of what you heard.
- When successful, resistance to talking often lessens and you begin to gain an understanding of the *participants experience*.

The "LEAP" Method

Empathize

- When and how to express empathy. *"If you want someone to seriously consider your point of view, be certain he feels you have seriously considered his."* (Amador, 2012, p. 67)
- Empathize with any feelings connected to alternate experiences (i.e. anger, elation, fear, worry, etc.)
- Empathizing with how one feels is not the same as agreeing a belief is true.

The "LEAP" Method

Agree

- Find common ground - it always exists!
- Look for motivation the participant has to change, if relevant (i.e. "get a job" or "complete residential treatment")
- Make observations *together* and ask questions. "What led you to completing your last residential program?"




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The “LEAP” Method

Partner

- Form a partnership! Achieve shared goals!
- Once you agree on goals (like completing residential treatment), you can collaborate *together*.



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Helpful Interventions continued

VCVC

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VCVC

- According to Western Massachusetts Recovery Learning Community (2019), **Validation, Curiosity, Vulnerability, Community** is:
 - A basic formula to be present and offer support to others
 - Non-linear, meaning you can jump between what make sense in the conversation
- Remember following any formula doesn't mean you get everything “right” or that there is never a disconnect in the connection
- Also, the goal isn't to have someone move through their distress by the end of the interaction but to have them feel seen and heard

Western Mass RLC is now Wildflower Alliance, rebranded in 2020: <https://wildfloweralliance.org/>

VCVC-Validation Examples

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- It makes sense that...
- Thank you for trusting me to tell me about this...
- I'd be [angry, upset, frightened] too...
- It's so awful that happened...
- I'm sorry to hear...

Credited to: Wildflower Alliance: <https://wildfloweralliance.org/>

VCVC-Curiosity Examples

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- What does it mean to you?
- What are you doing when you feel strong/energized?
- What might help you when...?
- What happened around the time you started feeling that way?
- What does that look like for you/in your life?


Credited to: Wildflower Alliance: <https://wildfloweralliance.org/>

VCVC-Vulnerability Examples

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- When something like that happened to me...
- When I have felt really angry like that, I...
- I'm feeling afraid, but I want to be here with you...
- I just want to be upfront that these limits exist...

Credited to: Wildflower Alliance: <https://wildfloweralliance.org/>




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VCVC-Community Examples

- Do you know other people who've struggled with...
- Have you asked anyone else about...
- Who are the people in your life that have helped in the past...
- Be a bridge, not a life raft...
- Are you familiar with (support group, online resource) where you may find people with similar experiences?

Credited to: Wildflower Alliance: <https://wildfloweralliance.org/>



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Helpful Interventions continued

CBT for Psychosis

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CBT for Psychosis

- Understanding and treating psychosis through a cognitive behavioral therapy approach.
 - Non-confrontational
 - Focus on specific symptoms (typically those that are distressing)
 - Explore beliefs relevant to experiences




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CBT for Psychosis

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- Therapeutic alliance
 - Agreement on goals
 - Empathy
 - Positive regard
 - Stages of change
 - Collaboration




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CBT for Psychosis

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- Psychoeducation
 - Symptoms and diagnoses
 - Co-occurring disorders
 - Nature of recovery




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CBT for Psychosis

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- Stress-vulnerability model
 - Protective & risk factors
 - Reoccurrence prevention, WRAP, or other self-management plans



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CBT for Psychosis

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- Coping with distressing symptoms
 - Breathing & relaxation
 - Thinking & feeling connection
 - Thought diary or analysis
 - Experiment record
 - Problem solving



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Helpful Interventions continued

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The Alternate
Experience Self Help
Group

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The Alternate Experience
Self-Help Group

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- Credit to **The Hearing Voices Network** whose principles include:
 - Moving away from diagnostic labels and *leaning in to individual stories, personal life experiences, and cultural context.*
 - The problem is not hearing voices itself, but rather *the difficulty with navigating the experience.*
 - People who hear voices can cope with their experiences by owning and making meaning of their voices.
 - Dialogue with one's voices is encouraged AND can change the relationship one has with their voices.

Check it out at: <https://www.hearingvoicesusa.org/>

The Alternate Experience Self-Help Group

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- Self-Help Meeting Format (similar to Alcoholic Anonymous) except solely focused on “Alternate Experiences”.
- This is not just a place for those who hear voices; any experience that is usually viewed as unusual or odd are welcome.
- No judgment zone, participants can share anything without the fear of consequences (like being hospitalized) except for situations like self-harm or imminent risk.

The Alternate Experience Self-Help Group

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- Supports healing and empowerment for individuals who have been impacted by life-interrupting challenges.
- An opportunity for individuals to come together, joined by shared goals and values that incorporate a fundamental belief that there are many ways to understand hearing voices, seeing things others do not see, and/or other unusual or commonly misunderstood experiences.

The Alternate Experience Self-Help Group

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- This group is a place of trust, respect, equality, acceptance and mutuality. The group starts from a place of acknowledging three freedoms:
 - Freedom to interpret experiences in any way,
 - Freedom to challenge social norms, and
 - Freedom to talk about anything.

Conclusion

- “Everyone is different, everyone’s relationship and status with their experiences are different, for them to know it is a struggle and its not easy living with ‘Alternate Experiences’”
- “What I would like clinicians to know about alternate experiences is that at their core they’re the same as regular experiences. The experience is the same it just happens to be false. This produces a good deal of confusion, frustration and very unhelpful stigma. It is very difficult to explain to someone that you know something is false yet you feel compelled to respond to it.”
- “Everyone is different, Experiences are different, individualize how you respond.”

Additional References and Resources

Amador, X. (2020). *I Am Not Sick, I Don't Need Help! How to Help Someone Accept Treatment - 20th Anniversary Edition* (20th Anniversary Edition). Vida Press.

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Questions?





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Thank You!

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