Moving Beyond Current Treatment: Responding to Extreme States With Compassion and Dignity

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Abstract
Newer research around extreme experiences is showing that recovery is far more prevalent than has been represented in the past. In addition, some aspects that have traditionally been considered the first line of treatment are now being found to be less effective than once believed or even harmful. However, approaches that combine new information, compassion, and that restore dignity to the individual are finally being recognized as the underpinnings of successful outcomes. Individuals who have gone through an extreme state deserve to learn about the impact of cultural aspects and childhood experiences on such. They should be reminded that many will experience positive growth from the extreme state itself. It should be normalized how frequently these experiences arise throughout the world and how often people do recover. It is important for individuals to understand the beneficial impact of enhancing relationships and connections in their daily life and of fostering empowerment for themselves and their choices. By incorporating research findings and inviting the individual to seek out a meaningful life, as determined by themselves, people can and do recover from these experiences.

Keywords
clinical psychology, compassion, coping, cultural competence, positive psychology, posttraumatic growth, schizophrenia, psychosis, quality of life, resilience

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Stepping Away From The Traditional View

Mainstream psychiatry has primarily portrayed the occurrence of extreme states, otherwise known as the experience of psychosis, in a negative light. Diagnoses such as schizophrenia have often been described as a permanent and deteriorating condition. Clients and families have been told this for generations. When we look more deeply into the research surrounding these states, however, what we find invites questioning of these more traditional views. It also provides direction in how to connect with these individuals in a more supportive way.

Some concerns point to the diagnosis and representation of the experience itself. Researchers have questioned the reliability and validity of the diagnosis of schizophrenia (Bentall, 2009). Others point out that experiences of psychosis actually do occur in the overall non-mental health population between 5% and 28% (Myers, 2011). In addition, these experiences do not necessarily persist or worsen over one’s lifetime as originally portrayed (Wunderink et al., 2013).

Cultural aspects must be taken into account. Experiences of psychosis are found to be more common among ethnic minority groups (van Os & Reininghaus, 2016; Zammit et al., 2010). Newer research is showing these extreme states to be linked with “childhood social adversity, childhood abuse and maltreatment, poverty, and a family history of migration” (Hickey, 2017; Polese et al., 2019). Unfortunately, the influence of clinician bias and potential racism has been found to be present in our country with African Americans being 3 to 6 times more likely to be diagnosed with schizophrenia (Bresnahan et al., 2007; Hawkins, 2019).

Current treatments do not offer the relief one would hope. Medications alone are seen as inadequate to address the needs of the person, often bring about multiple side effects or detrimental impacts on motivation toward recovery, and in total may decrease symptoms but not improve overall functioning (McGorry et al., 2013; Polese et al., 2019). The number of people for whom the medications are ineffective can range from 30% to 60% (Lowe et al., 2018; Polese et al., 2019). Furthermore, antipsychotic medications have been found to at times directly contribute to a dopaminergic supersensitivity effect, decreases in gray matter volume in the brain, and “permanent neurological damage” (American Psychological Association, 2020; Fusar-Poli et al., 2013; Polese et al., 2019). And finally, these individuals have been found to be dying 20 years earlier than the rest of the population (Laursen et al., 2013).

A new foundation for treatment is greatly needed. Newer research on individuals who chose not to use antipsychotic medications are showing superior
outcomes in long-term follow-ups (Harrow et al., 2017; Wunderink et al., 2013). The tenants of Open Dialogue are so effective that in Western Lapland, where the program originates from, they are able to provide support so quickly that people are not experiencing the symptoms for the required 6 months to receive a diagnosis of schizophrenia. As a result, their overall incidence of schizophrenia is 0.2% instead of the 1% to 2% in the rest of the world (Seikkula et al., 2006). Also as a result of building up awareness of their programs and services they have reduced the duration of untreated psychosis (DUP) to 3 weeks (Open-dialogue.net, 2019). The duration of untreated psychosis in the United States currently is 74 weeks and is a main concern as longer duration without adequate treatment predicts poor outcomes (Hardy et al., 2017).

**Making Meaning and Normalizing**

If we are to look beyond the traditional view, we find the experience of extreme states and altered experiences to actually be a rich and deeply meaningful experience for many individuals. Research has shown positive growth, increased insight and clarity, improved relationships, and increased spiritual connection following the altered state itself (Jordan et al., 2016, 2019). An increased appreciation of life, increased integration and personal growth, and increased posttraumatic growth have all been found in relation to experiencing extreme states and how they are allowed to be addressed personally afterward (Jordan et al., 2019; Mapplebeck et al., 2015; Pietruch & Jobson, 2012).

Viewing extreme experiences on a continuum where all individuals fall depending on the stressors in their life, such as the Stress-Vulnerability Model, is an alternative viewpoint that many researchers and individuals with lived experience embrace (Landa, 2017; van Os & Reininghaus, 2016). Identifying the potential that these experiences may provide some form of protection as a defense mechanism against psychological stress is another viewpoint that is respectful to the individual and the experience (Laing, 1967; Vaillant, 2011).

With so much research pointing to extreme experiences being a more common and understandable reaction to our world, we want to invoke not only exploration of the experience but also supportive connection around such. And that includes the caregiver or companion to the person as well as the person’s relationship with themselves and their experience.

The ability to foster this is enhanced by reassessing our own use of terminology and how it impacts the person. Research finds that individuals who believe they have a brain disorder have a negative impact on self-worth and belief in the potential for recovery (Read & Harré, 2001). Respectful use of
terms that individuals with lived experience use themselves can go a long way to promote their positive self-worth and agency in describing their experience. These can include altered states, non-ordinary experiences, a spiritual emergency or spiritual crisis, a Kundalini awakening, or possibly a Hero’s Journey. Wording for the person going through the experience can include client, consumer, mental health survivor, expert by experience, individual with lived experience, and neurodiverse individuals.

Descriptions of the so-called “symptoms” also deserve to be adjusted for individuals who find the clinical terminology to be dismissive or invalidating. Alternatives for hallucinations may include voice hearing, visual images, intuitive knowing, or receiving input from one’s ancestors. Instead of the phrase delusion perhaps extreme belief or new perspective. And instead of paranoia, which unfortunately tends to now imply the person is imagining things, one might use intense worry, concerns, fears of safety, concerns with trusting others, or a sense of being targeted. Many individuals will not mind the more clinical jargon but these alternative terms are a wonderful option for those who do as a way to promote respect for persons experience instead of implying it is something else.

One aspect of showing respect is by fostering choice, empowerment, and a strengths-based approach which is seen in the Recovery Movement. This can include helping the person define their own perception of quality of life aside from any label (WHOQOL-BREF, 1996). We want to foster connection with supports who believe in recovery and the person’s ability to get through the difficulties of their experience, finding a personal identity, and making meaning and purpose in one’s life which can include meaning from the extreme state (Leamy et al., 2011; Morris, 2019; Slade et al., 2016).

We want to reinforce the worthwhile aspects of connecting with peers who have gone through their own intensity and other supports who understand their own version of the experience and who resonate with the feeling of stigma. And highlight awareness that these needs differ depending on if the individual is going through a first occurrence or when the person has been going through this for longer periods of time (Ganguly et al., 2018).

Providing information on how common these experiences are in the world is another way to support and normalize one’s experience. Related to voice hearing, 1 out of 10 people in the world will hear or see something that others do not in their lives (Hearing Voices Network, 2019). That is an extremely large number of people, especially when we remember that only 1 to 2 out of 100 will have a diagnosis related to such. In addition many people have kind or supportive voices that they benefit from and want to remain in their lives (Romme & Escher, 2000). During functional magnetic resonance imaging studies of voice hearing, the auditory section of our brain is active just as
when hearing other things throughout ones day (Ikuta et al., 2014). Also the experience of voice hearing has occurred among many well-known individuals including Anthony Hopkins, Gandhi, and Sigmund Freud (Hearing Voices Network, 2019). Providing this information to people helps them to understand they are experiencing things similar to millions of others in the world.

**Therapy and Personal Agency**

Informing people of the benefits of effective treatment is another aspect of the caregivers’ role. Research shows that psychotherapy with an experienced therapist can bring about a decrease in discomfort and enhanced clarity in life (Karon & VandenBos, 1981). Also a longer length of time in therapy promotes changes with longer standing and negative symptoms (Polese et al., 2019).

Using the empowering themes among psychological theory provides a reminder of ways to interact with our people. We want to base our connection and support of the person on the views of Open Dialogue which promotes an equality in those present to contribute and make sense of the needs of the whole (Aaltonen et al., 2015; Olson et al., 2014). Invite focus and reminders of the enjoyable parts in one’s life as Positive Psychology incorporates into their work. This can include identifying one’s own strengths and also increasing gratitude, supportive relationships, and finding positive aspects where we may previously have only focused on the negative (Slade et al., 2016). Identify what we value in life and continually assess whether we are taking effective action toward such as in Acceptance and Commitment Therapy (Morris, 2019; Bach, 2015; O’Donoghue et al., 2018). Invite understanding and an overarching formulation of what is occurring in one’s life without pushing a sense of right or wrong such as with Cognitive Behavior Therapy (Landa, 2017). Help invite acceptance of the experience and an openness to what comes into our awareness without needing to dwell or struggle with it such as with Mindfulness and Compassion-Focused Therapy (Newman-Taylor & Abba, 2019; Heriot-Maitland & Russell, 2019; Wright et al., 2014). And incorporate a respectful view of the person’s spiritual perspective with the awareness that spiritually transformative experiences have the potential to heal and be a “catalyst for growth” (American Center for the Integration of Spiritually Transformative Experiences [ACISTE], 2013; Clarke & Wilson, 2009; Grof & Grof, 1989).

In addition, be aware that therapy and psychiatry are not the only option available. Reinforce the person’s ability to find what will fit best for them and take action toward that. We want to foster a renewed interest in where the person would like their life to go once again that is based on the person’s
personal areas of interest (Kane et al., 2016). We want to learn from what has occurred in the past so that we can be more aware and able to prevent similar escalations into intensity in the future (Polese et al., 2019). This can include understanding their own personal examples of how intensity increases for them and what options will help prevent continued escalation or maintain at the current point more easily. Also take action to identify and bolster social and family support in one’s life (Morin et al., 2017).

Caregivers also deserve to have their own support. Family members involvement in treatment can enhance overall functioning and reduce relapse for the client, as well as, decreasing caregiver report of sense of burden (Claxton et al., 2017). Their own therapy can positively impact the overall climate in the family. In addition, family has the opportunity to benefit the person’s overall experience during both first episode experiences and also longer-standing situations. Therapists getting case consultation, their own individual therapy, and additional training is also a vital piece to being able to support someone going through an extreme state.

The Way Out Is Through

No matter the history of treatment for psychosis and extreme states, we have the opportunity to invite people into a more compassionate and supportive stance. The ways we connect with another who is going through these experiences can allow them a lifeline and a direction for their future. Please be open to the ways you invite hope and belief in the potential for them to have a wonderful life. And above all, be respectful and genuine in how you connect with them at all stages of their experience. In the words of the psychoanalyst Harry Stack Sullivan, “We are all much more simply human than otherwise.”

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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References


work functioning in schizophrenia. *Psychiatry Research, 10*, 267–274. https://doi.org/10.1016/j.psychres.2017.06.069


Hearing Voices Network. (2019, November 2). https://www.hearingvoicesusa.org/


**Author Biography**

**Chelsea Mackey** is a licensed psychologist in Sacramento California and currently works almost exclusively with individuals who have gone through altered states, voice hearing, or experiences described as psychosis. Previously the lead therapist at Kaiser Permanente’s Thought Disorder Program in the local area, she now works as an outpatient therapist at Vantage Point Center for Psychotherapy. She has provided continuing education trainings for PESI and Zur Institute both on working with and recovery from altered experiences. She is a member of the international society for psychological and social approaches to psychosis (ISPS) and has presented across the country and internationally on compassionate forms of psychotherapy for extreme states. She also supervises and consults with other therapists interested in enhancing their skills in this area. She believes deeply in all human beings ability to work through the experiences in life that have shaped them, and she is so appreciative to her clients for allowing her into their lives.