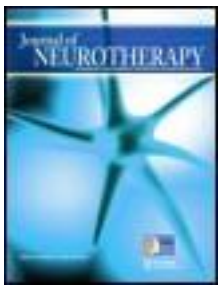

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Client Perception of the Neurofeedback Experience: The Untold Perspective

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Client Perception of the Neurofeedback Experience: The Untold Perspective

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BACKGROUND

Although many practitioners involved in neurofeedback see the amazing results on a daily basis, to this point clients have not had an opportunity to express their feelings about and during the process. This article gives a snapshot opportunity to look at neurofeedback for the treatment of anxiety disorders, from the client's perspective. This study took aim at reported quantitative healing and looked at the client's perspective of how that healing looks to the client on a daily basis. As concluded by Cacioppo (2004), it is the joint consideration of physiological and psychological perspectives that enriches theory and research.

ANXIETY

Anxiety disorders cause severe distress over time and disrupt the lives of individuals suffering from them. The frequency and intensity of anxiety involved in these disorders is often debilitating (American Psychological Association, 2007) and no matter at what age the brain starts to produce anxiety a person changes in relation to it (Wehrenberg & Prinz, 2007). As anxiety may manifest in a number of different ways including panic attacks, sleep disturbances, and mood liability to name a few, each client's needs in treatment may differ. Specifically, our brains defy reduction to simple cause-and-effect relationships and anatomical boundaries; many of the interactions are subtle to the point of invisibility (Cozolino, 2006). It makes sense then to find therapeutic ways of addressing anxiety that include regimens tailored to the individual, so that the translation from the therapeutic setting to everyday life has an effect that the client deems as healing.

The participants in this study underwent both qEEG-based and non-qEEG-based neurofeedback training to address anxiety diagnoses including panic disorder, generalized anxiety disorder, and social phobia. All clients underwent pre- and posttesting using the Brief Symptom Inventory (BSI), and all tested participants reported a decrease in the anxiety subscale as well as all other subscales measured by the BSI.

CLIENT PERCEPTION OF CHANGE

Studies of patient–practitioner communication have shown that the patient's (client's) perspective is often lost (Haidet & Paterniti, 2003). In addition, although documenting change is tantamount in the empirical research literature, documenting the effects of healing to a client's everyday life is sorely missing. By leaving out this vital information, practitioners assume that changes on assessment scores equal positive changes in every aspect of their client's life. Somehow

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practitioners miss the story of life when a diagnosis is no longer present. Practitioners may assume that reported changes in the therapy room mean positive changes when the client returns to her own environment and relationships. By looking at the effects of therapy, this study opened the door for practitioners to have a greater sense of connection to their clients during treatment and a deeper contextual understanding to keep in mind while planning for treatment.

Genuine evidence-based practice actually presupposes an interpretive paradigm in which the patient experiences illness in a unique and contextual way (Greenhalgh, 1999). In other words, each patient's experience of illness, or in this case anxiety, is unique. Therefore, true evidence for treatment may only lie in what the patient posits is true for her experience. Greenhalgh stated that it is only within such an interpretive paradigm that a clinician can meaningfully draw on all aspects of evidence to reach an integrated clinical judgment—his or her own case-based experience, the patient's individual and cultural perspectives, and the results of rigorous clinical research trials and observational studies. It is hoped that listening to the narratives of client's posttreatment will encourage further exploration of implications for healing and treatment choices.

PROCEDURES

This study was conducted in the researcher's private practice and incorporated quantitative as well as qualitative data, although the researcher's goal in the current project was to tap into an as-of-yet underreported aspect of neurotherapy by eliciting patient experiences of treatment. The approach utilized the BSI (Derogatis, 1983) and a pretest, posttest format. A pretest was performed on all of the participants; participants then underwent a combination of talk therapy and EEG biofeedback. The same posttest was administered at the conclusion of treatment. The results of the BSI were evaluated to determine if there was a direction of change in symptoms. Traditional research dictates that a decrease in scales on the BSI would equal healing, so it was hypothesized that there would be a decrease in symptoms as shown by a decrease in rating across subscales of the BSI. An interview was then conducted with each participant in an attempt to elicit his or her experience of treatment effects that may not be explained by a pen-and-paper assessment, as well as to extend an invitation to the client to consider aspects of the neurotherapy process that may be beneficial to future neurotherapy clients.

RESULTS/FINDINGS

Results revealed that overall, anxiety was still present but manageable and that each person interviewed felt a sense of control over symptoms that was not present prior to treatment. The following is a summary of presenting difficulties and client narratives of healing.

After or during neurotherapy all participants were interviewed with the following results:

Subject 1 was a 20-year-old college student, symptoms of anxiety primarily related to social situations. She felt a strong sense of isolation and worry over people laughing at or talking about her. She was worried she would not communicate correctly, prohibiting her from daily activities such as ordering food from a drive-thru. At the time of referral she was medicated with Lexapro.

Q. Do you feel you have healed from the original issues you hoped to address?

"I have healed from the issues I originally hoped to address 90%. My life has completely turned around from when I first started therapy. I was depressed and felt as if there was nothing I could do to stop myself from feeling this intense anxiety. I experienced an exponential improvement in my anxiety level. Overall, I feel that the results of my therapy far exceeded my original expectations.''

Q. Have there been any changes in relationships that were significant to you?

"My father and I have always had a distant relationship and he has found it hard to express his emotions verbally. After I

finished treatment, I found that as I began to change, so did he. He began to open up more, and even recently began to express his affection not only with hugs, but also by actually saying the words, ''I love you,'' which I hadn't heard since I was a child. In addition to this specific example, I have found an improvement in all of my relationships, and find it easier to open up to people and share my thoughts and feelings, without fear of ridicule.''

Subject 2 was a 42-year-old married mother of four who home-schooled her children. She experienced ongoing panic attacks that worsened into agoraphobia. She had been symptomatic for 11 years and received multiple diagnoses from multiple practitioners. Her family was very invested in her ''illness'' and played a significant role in her care. She was medicated with Xanax and Lexapro.

Q. Do you feel you have healed from the original issues you hoped to address?

''The anxiety has not completely gone away but has definitely gotten better. I rarely have panic attacks and I am better able to control them when they do happen.''

Q. Have there been any changes in relationships that were significant to you?

''Each little step has changed or improved a relationship so it's hard to narrow it down. I can tell you I have taken back the finances and when I was having anxiety I couldn't handle that. I have completely taken myself back. The unexpected thing that happened was that when I felt I was managing anxiety better, my husband and I started fighting. We hadn't fought in eleven years but it was like all of the sudden I could say what I thought in any situation. I think he got used to me letting him make all the decisions. We went to couples therapy and are doing better but he will be the first to tell you that getting over anxiety was hard for him, too.''

Subject 3 was a 14-year-old high school student with one older sibling. Her father passed away when she was 10 and she began experiencing symptoms shortly thereafter. Her panic symptoms prevented her from attending school without going to the counselor or calling her mother to come and get her on a daily basis. She had pervasive worry and fear over death and a constant sense of impending doom.

Q. Do you feel you have healed from the original issues you hoped to address?

''I think the anxiety is pretty much gone except for some exceptions like regular people that get anxious about things but other than that I don't feel it, but if I do it's like ok this is anxiety and I don't think about it and it just goes away.''

Q. Have there been any changes in relationships that were significant to you?

''Me and my mom's relationship got stronger, and my brother, too because I can understand what he's going through when he's mad and I know it's anxiety. If anything my relationships have gotten stronger.''

Subject 4 was a 37-year-old married male who suffered with panic attacks for approximately 3 years before seeking neurofeedback. He was referred by a cardiologist who, after various medical tests had to ''convince'' the client his problem was psychological. The client took himself to the emergency room an average of once a month over a 3-year period. He stopped exercising entirely because exercise would increase his heart rate. He was afraid to drive and was about to resign from his job as an engineer.

Q. What was your first impression of neurofeedback? What did you think when the idea was first introduced? What finally prompted you to pursue neurofeedback as a treatment modality?

''When my primary care physician told me of a way to deal with anxiety without medication I was ready to get started right away. What sent me into treatment was the idea of taking medication did not sit well with me.''

Q. Describe your experiences during neurofeedback. For example, did you have any adverse effects or changes in behavior, emotion, or relationships while in therapy?

''All my experiences during the process were positive. I started feeling better right

away. I had no issue with my behavior except that I was feeling better and was able to start doing things without the fear of something happening to me.''

Q. What would have been beneficial to know prior to beginning treatment? What advice, if any, would you give potential clients of neurofeedback?

"I did not do any research on the internet prior to starting therapy because sometimes the internet can give answers that are very conservative causing a preconceived notion that a particular treatment may not work. My advice to someone is to try this before you start down the path of medications.''

''It has been over one year since I completed my treatment and every once in a while when I have trouble sleeping I will get symptoms but nowhere near what they used to be. My advice would be to start treatment as soon as possible.''

Q. If I knew then what I know now I would say?

''Why didn't I believe my primary care physician and start the treatment sooner? However if I would have started treatment sooner I would not have met so many nice nurses and doctors at my local emergency room!''

Subject 5 was a 33-year-old married male and father of two small children. He experienced extreme fear and panic for 3 years and became fixated on his breathing ''because of the heavy chest.'' He feared choking every time he ate and feared harm would come to his children when they were under his care if he were to pass out. He would cry in public for no apparent reason and had to stop all hobbies that he once enjoyed. He had been suicidal for 2 of the 3 years he experienced anxiety and consequently sold his favorite guns.

Q. Describe your experiences during neurofeedback. For example, did you have any adverse effects or changes in behavior, emotion, or relationships while in therapy?

"When I began treatment I felt anxious because of the new environment and concern over what I would have to go through. There have been times during therapy where my levels of anxiety did increase to an uncomfortable level. I think the worst it has gotten during treatment was to a level 4 out of 10, 10 being the worst. However as I learned to control the anxiety I could drop from a level 4 to a level 2 in under 40 seconds. I could then drop from a 2 to a 0 in 6 minutes. That used to take me hours by myself and it would generally escalate to an 8 or 9 before it would begin to subside.''

Q. What would have been beneficial to know prior to beginning treatment? What advice, if any, would you give potential clients of neurofeedback?

"The best part about therapy is the realization that I am not the first person with this condition and that it is not abnormal or life threatening. I have now been in treatment for almost two months going religiously twice per week. There have been times after treatment where I felt anxiety free for two days. This doesn't seem like a lot of time but considering I was anxious every day, this was the beginning of my assent to health.''

Q. If I knew then what I know now I would say?

"There are also times after treatment when my anxiety felt worse than ever. It was part of my process but I had to keep telling myself I am winning with every treatment. Last Friday after treatment I felt better than I had in two years. I actually stopped and wondered what anxiety felt like. I was out running errands like I did pre-anxiety. I actually felt youthful again. Granted this only lasted a couple of days but believe me it was a great couple of days.''

Q. Did you experience "waxing and waning" of symptoms during healing? Were there times when you questioned whether or not you should be undertaking treatment? What kept you going?

"Throughout the sessions I do have periods of waxing and waning where I will feel great one day but bad the next and vice versa. At times I did question whether the treatment was actually working but I remembered my therapist warned me about

potential waxing and waning before we began treatment. If treatment continues on this pace there is no doubt in my mind that I can be well again. I actually feel myself getting better week by week and for the first time in years I think I might actually beat this thing.''

Interpretations

Although this article is a report of client's experiences, it is not meant to be a formal qualitative study but rather a glimpse into the client's perspective of the process of neurotherapy. Also and most important to the emphasis of this point, although pen-and-paper assessments often report healing from pre- to postneurofeedback training, the true experience of healing can be elicited only by asking our clients about their impressions of the process. Major points learned from this study include the following:

1. Anxiety symptoms may persist after neurofeedback training but are much less severe than the original symptoms and more manageable for the client.
2. Reports of decreased symptoms on pen-and-paper assessments can indeed correlate with the real-life experience of decreased symptoms; however, the degree of healing is difficult to assess with pen-and-paper assessments.
3. There is a plethora of information about our client's experiences during and after the neurotherapy process that may go untapped without specifically questioning the client.
4. Not only do EEG changes reflect improvement in symptoms but they also may indicate changes in other aspects of clients lives that are significant to them, such as relationships that are significant to them.

During the interviews, the subtext of the participants' dominant story emerged, enabling them to change their stories of being overwhelmed and consumed with anxiety to that of healing and being able to cope with whatever remaining symptoms they were experiencing. Because these interviews were done at a minimum of 12 months after treatment for the first and second participants and 4 months for the fourth participant, it may be inferred that the changes experienced by the participants are lasting.

One may notice a change in the way the participants thought about anxiety and its effect on them. For example, dominant conversation can become problem saturated, whereas the client's strengths and resiliency may become overlooked, especially during times of increased symptoms. The subordinate storyline that may have been forgotten during client's struggles was one of healing and of regaining a feeling of control over their anxiety. The development of these subordinate stories may contradict a sense of helplessness and worthlessness (White, 2008). With the development of subordinate or alternative stories, positive relational changes are possible. In other words, the overall feeling was that relationships have improved, and those relationships often assisted in the process of healing.

Although it is difficult to determine exactly what neurological changes took place within the participants' brains with this study design, the outward effects of these changes were noted throughout these participant's stories.

CONCLUSIONS

When deciphering what may be helpful within the realm of neurotherapy, it may be apparent that treatment combines a relationship, moderate levels of arousal, thinking, feeling, and a story. This study emphasizes the importance of communicating with the client about his or her perceptions of wellness. There appeared to be a similarity between reduction of anxious symptoms and results reported on the BSI; however, what those scores actually meant could not have been ascertained without asking these participants about their experiences.

These results are an example of the changes that are possible as well as probable when symptoms are addressed, therefore necessitating the realization by the practitioner that what is done in the context of

treatment has implications in many aspects of a client's life. It may be important for the practitioner to both recognize and ask about relational changes to create a safe environment that nurtures exploration of a multifaceted treatment approach.

Directions for Future Research

Recommendations for future research should include further exploration of the correlation between pen-and-paper research and personal narratives of healing. Although the level of symptom logy in self-report measures may decrease, it is difficult to determine exactly how that translates to everyday life without asking clients. Exploring the narrative of the process as well as the end result of treatment may give the practitioner a better understanding of the client's point of view and may allow the client to explore the untold subtext of his or her story that may influence those relationships that are important to the client. Practitioners must be aware that symptom reduction means different things to different individuals and therefore an explanation of assessments should be encouraged. Future research should address ways to do this within the current time constraints experienced by most practitioners.

Future research should replicate this study with other diagnoses. However, regardless of the population studied, researchers should be cautious when advocating for a particular treatment approach that may leave little room for the personalities and relationships of clients to influence treatment outcome. Therefore an individualized approach including a combination of therapies may be the future of addressing change instead of the modernist ideas of a grand theory to explain both behavior and what therapists "should" do to address particular diagnoses.

Finally, researchers should continue to ask what has been helpful about treatment and what healing has looked like when translated into everyday life through a formalized qualitative or mixed-method study. The importance of client perception may be the key to long-term beneficial results. With these suggestions in mind the researcher should be careful not to "prescribe" a theory of change, especially when working with an integration of therapies.

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