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THE BENEFITS OF SUPPORT GROUPS FOR INDIVIDUALS WHO EXPERIENCE AUDITORY AND VISUAL HALLUCINATIONS

Joseph Stewart

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A Project

Presented to the

Faculty of

California State University,

San Bernardino

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In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

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ABSTRACT

Four members of a peer-support group that focuses on experiences of auditory and visual hallucinations participated in interviews to explore ways that support groups benefit this population. The researcher had special interest in the domains of reduction of discomfort, reduction of stigma, and increase of functioning. This qualitative study used thematic coding to analyze interview data. Regarding the ways that participation in the support group benefits members, eight themes were identified: the group providing a safe space, growth in communication skills, meeting belongingness needs, participation increasing euthymia, increased ability to cope with symptoms, normalization of people experiencing hallucinations, addressing stigma surrounding hallucinations, and increased hopefulness among group participants. Social workers and mental health professionals are invited to re-examine their personal biases regarding audio and visual hallucinations and consider treatment options beyond the medication-first paradigm prevalent today.

ACKNOWLEDGEMENTS

DEDICATION

For my late grandma Mary Lux. In many ways she navigated her voices and visions alone. She would have greatly benefited from friendships and mutual support with others who shared similar experiences, and she had much to offer in return.

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CHAPTER ONE:

ASSESSMENT

Introduction

Chapter one provides an overview of this research into support groups for those who experience hallucinations and describes why this research is important. An explanation of the use of the post-positivist paradigm is provided and the theoretical orientations which will guide the research are discussed. A literature review is provided which explores: the prevalence of hallucinatory symptoms, causes and contributors to the issue, impacts of the issue, and existing interventions. The chapter concludes with an exploration of the ways this study may contribute to social work practice.

Research Focus

This research seeks to discover how attending support groups can lead to quality-of-life improvements for individuals who experience hallucinations such as hearing voices or seeing visions. Interviews will be conducted with members of a peer support group centered around hallucinations in order to discover which elements of group attendance benefited participants. Three areas will be explored in order to gain a well-rounded picture of quality-of-life improvements: client's perception of stigma surrounding hallucinatory symptoms, client's level of distress experienced due to symptoms, and client's perception of their functional impairment due to symptoms.

Individuals who live with ongoing auditory and visual hallucinations have unique life challenges and often struggle to find effective treatment (Kvrgic et al., 2013). Self-stigma is a barrier to effective treatment, and clinicians often struggle to build the levels of trust with clients that would allow for full disclosure. Clients often feel that they are alone in their experiences of hallucinatory symptoms and feel hopeless that their symptoms or levels of impairment will improve. Support groups are composed of peers who all share similar symptoms, which provides unique opportunities for growth and exploration of wellness. However, more information is needed about specific elements within support groups which bring benefit to participants.

Paradigm and Rationale for Chosen Paradigm

This study will employ the post-positivist paradigm. The focus is to learn what elements of peer support groups are most effective in recovery from mental health, so this inquisitive and qualitative research paradigm is most appropriate. According to Morris (2013) the post-positivist paradigm is an approach which gains information from the bottom up. New ideas, themes, and lessons emerge as the research subjects are explored. This paradigm does not reject the assumption that objective truth is obtainable, but it assumes humility to expect that there may be fundamental issues related to the research material which are not understood at the outset. The processes of data collection and data analysis occur in tandem, offering room for flexibility, nuance, and results which were not predicted.

The post positivist paradigm is the best fit for this research because the hope of the research is to find and understand factors within the group which add value to the lives of group participants. The themes of stigma, personal distress, and functional impairment can be explored in ways which are authentic to research participants. Further, the conversational quality of post-positivist research allows for important clarifications in the research process which would not be possible with a rigid and operationalized study. People in this client population are prone to being misunderstood, so the ability to lean into points of confusion serves to improve the quality of the research and respect the research participant.

Literature Review

Auditory and visual hallucinations are experienced by people both with and without diagnoses of schizophrenia. Although hallucinations are perhaps the most well known component of schizophrenia, De Leede-Smith & Barkus (2013) suggest that the strongest evidence points to hallucinations as a phenomenon distinct from schizophrenia. The prevalence of auditory and visual hallucinations is higher than many would expect, while the causes are not fully understood. The impact hallucinations have on individuals varies with the intensity of the hallucinations as well as how hallucinations are interpreted. The most common intervention for treating hallucinations in Western societies is to prescribe antipsychotic medications, while other global societies address hallucinations by finding meaning and cultural purpose in the phenomenon.

Prevalence of Auditory and Visual Hallucinations

        Auditory and visual hallucinations are more common than many believe but are often transient in a person's lifetime. De Leede-Smith & Barkus (2013) conducted a comprehensive review of scientific literature regarding hallucinations in Western societies. Most estimates put the prevalence rate of experiencing auditory or visual hallucinations between 9 and 15 percent in the general population. Rates are between 5 and 15 percent in adolescents, primarily because the age of onset varies from person to person.

        In people whose hallucinatory symptoms are not at the clinical level, the median frequency of voice hearing was an occurrence approximately every two and a half days which would last two and a half minutes. In this population, hallucinations are rated as being controllable more than 60% of the time and they rarely cause distress to the individual. For voice hearers in the clinical population: voices are only controllable 17-20% of the time and cause moderate to severe distress and disruption to daily functioning. The average age of onset in the non-clinical population is between 12 and 14 years old while the average age in the clinical population is closer to 21 years of age (De Leede-Smith & Barkus, 2013).

         It is important to also examine prevalence rates in other countries. Siddi et al. (2019) found in their cross-national research that prevalence of audio or visual hallucinations varied widely from country to country. While they found the U.S. rate to be around 10%, reported rates ranged from .58% in the Czech

Republic up to 32% in Nepal. According to Temmingh et al. (2011) rates of hallucinations in African nations range from 9% to 28%.

<u>Causes of Auditory and Visual Hallucinations</u>

Researchers have identified several possible causes of auditory and visual hallucinations, but in almost every case more research is required. De Leede-Smith & Barkus (2013) noted that symptoms often appear during mid- to late adolescence and therefore analyzed theories which sought to explain how brain changes during this time might be involved. It is possible that the onset of rapid hormonal and neurodevelopmental changes during adolescence are involved with the onset of hallucinatory experiences. During this time of life the brain rapidly increases the number of connections between different brain centers, and does not aggressively prune these connections until the individual transitions into adulthood when brains lose neuroplastic malleability. The biopsychosocial perspective offers the possibility of understanding hallucinatory symptoms, but more research is needed.

Bartels-Velthuis et al. (2010) explored correlations between auditory vocal hallucinations in middle childhood and various childhood factors. They found no gender differences in likelihood of developing symptoms. They found evidence that children born with an APGAR score less than 7 may have a higher chance of experiencing hallucinations or developing mental disorder. The authors were surprised to find that living in an urban population was strongly associated with a lower likelihood of developing auditory or visual hallucinations. Oddly, those in

urban environments who did experience hallucinations were more likely to be severe and have greater functional impact on the individual. More research and larger sample sizes were recommended.

Impacts of Auditory and Visual Hallucinations

Bartels-Velthuis et al. (2010) found that 15% of the children they interviewed who experience auditory vocal hallucinations endured substantial suffering because of those experiences. Voices and visions can cause anxiety, interfere with thinking tasks, and create challenges in creating or maintaining relationships. Many people who experience hallucinations feel confused, isolated, and tormented.

Kvrgic et al. (2012) reported that people who experience hallucinations often choose not to share about these experiences due to fear of social consequences. Secrecy and withdrawal are common coping strategies for those who have applied negative stereotypes to themselves about mental illness. Levels of self-stigma are inversely proportional to both help seeking behavior and devotion to mental health treatment. Profound isolation may result, along with lower likelihood of success in school and in career (De Leede-Smith & Barkus, 2013).

For individuals with greater severity of symptoms, there is a higher likelihood that they will be unable to understand or cope with their symptoms (De Leede-Smith & Barkus, 2013). This rises in association with increased stress,

anxiety, and psychotic symptoms. Those who experience frequent, disturbing, or severe hallucinations have a greater risk of being incarcerated or hospitalized.

Existing Interventions

The classic treatment for symptoms of auditory or visual hallucinations is to prescribe antipsychotic medications and provide support with psychotherapy (Sommer et al., 2012). Antipsychotic medications are the only known drugs which are capable of reducing severity of hallucinations. Medication options include haloperidol, olanzapine, amisulpride, quetiapine, and ziprasidone. Sommer et al. (2012) found all of these medications to be roughly equivalent in effectiveness, reducing symptom severity by about 60% over one year of treatment. There was more variance between the rates of discontinuation between medications, with amisulpride and olanzapine having the lowest discontinuation rates. Clozapine may be the most effective antipsychotic medication but due to need for monitoring and registration it is often prescribed after other medications failed to provide benefit. Discontinuation of antipsychotic medications are normally due to dissatisfaction with drug side effects (such as sedation and weight gain) or the belief that medications are no longer warranted.

Although antipsychotic drugs are the most established treatment option for schizophrenia and related hallucinations, Somer et al. (2012) were unaware of any clinical trials examining the effectiveness of these drugs for the sole purpose of treating hallucinations. The research team also noted that cognitive behavioral

therapy can be effective in reducing symptom severity because successful CBT lowered anxiety associated with catastrophic judgments.

A growing body of work indicates that recovery orientation and lowered self-stigma are associated with reduced distress and reduced impairment due to auditory and visual hallucinations. Kvrgic et al. (2012) found that a recovery orientation, which is a personal approach to symptoms focused on growth and learning along with less self-stigma, increased the likelihood of positive outcomes in the therapeutic process. More generally, recovery-oriented practice views recovery from mental illness as a personal and social journey which constantly evolves towards wellness (Chester et al., 2016). A recovery perspective tends to positively impact individuals in multiple areas of their lives. (Winsper et al., 2020).

Literature Review Conclusion

This research project will investigate an important avenue of support beyond medication for those who experience auditory or visual hallucinations. The number of Americans who have these experiences may be as high as 15%, and even among those with mild cases their symptoms are uncontrollable 40% of the time. The causes of hallucinations aren't fully understood, but research has made it clear that self-stigma amongst voice hearers leads to worsened experiences of their symptoms. Antipsychotic medications are a solution that is far from perfect while peer support groups provide the opportunity for people to have hallucinations to develop a recovery orientation and to reduce self-stigma.

Theoretical Orientation

This research does not seek to impose any theoretical assumptions over the research material because of the exploratory nature of the research. However, the research will be guided by the mental health recovery model. This model informs the research design and philosophy of this work because it assumes clients experience success because of strengths they discover or skills they learn, and that recovery learning often occurs within recovery-oriented relationships (Winsper et al., 2020).

The mental health recovery model is a theoretical model, not an explanatory theory. According to Chester et al. (2016) the mental health recovery model is somewhat fluid in definition but is characterized by the non-linear process by which a person with mental illness increases stabilization within their life and achieves their own goals for their life. Systematic reviews have shown that recovery-oriented interventions are associated with superior outcomes in functional, existential, and social realms (Winsper et al., 2020).

Assuming an approach rooted in the recovery model will help research partners understand the research focus because interviewers will be looking for strengths and personal victories within the research participants. This model informs this research because it asserts that treatment of mental illness is a process that occurs as learning and empowerment increase. The recovery model meets the symptoms and challenges of individuals who have mental health conditions with hope and optimism. The mental health recovery model implies

that strengths, effective strategies, and coping strategies are there to be discovered within the research conversations.

The relational aspects of the recovery model fit well with the group aspects of this research. Interviews will focus on elements within the group that increase trust and mutual respect. Kvrgic et al. (2013) found that levels of trust, or therapeutic alliance, are associated with reduced self-stigma and increased insight into personal mental illness. The group nature of this research is critical to the assumption that the recovery process is leading towards increased wellness.

Contribution of Study to Social Work Practice

This research will yield insights which will help social workers to make better recommendations for treatment options for clients who experience symptoms of auditory and/or visual hallucinations. The research will utilize direct testimony from those who attend a peer support group for auditory or visual hallucinations to learn more about how the group has been helpful to them in their recovery journey. Knowledge gained will increase social worker's professional insight and may also assist in the referral process for clients.

This research will yield insights which will allow clinical social workers to lead support groups that are more beneficial to clients. Those who lead support groups for this client population will gain firsthand knowledge of elements which have been beneficial to others who have experienced similar symptoms. Group facilitators may also derive personal inspiration by learning about recovery

successes in other groups- it can be discouraging for treatment providers if progress in clients is not often observed.

Finally, this research can be a point of comparison for future studies. Future research could build on this work by conducting interviews in various treatment settings and with different demographics. This could allow for cultural differences in the treatment of auditory and visual hallucinations to be better understood and better provided for. Increased qualitative studies may yield a standardized or recommended set of practices for support groups for this population. Such a set of practices could be operationalized and studied via a positivist research protocol.

Summary

This study seeks to learn from members of a peer support group centered around symptoms of auditory and visual hallucinations. Research will be conducted from a post-positivist perspective and will unfold as lines of inquiry are drawn while discussing stigma, distress, and impairment associated with hallucinatory symptoms. A literature review was provided, which established the prevalence of aforementioned symptoms, the distress and impairment often caused by them, and the need to explore supports beyond medication. Attending peer support groups may lead to quality-of-life improvement for those who have experiences of hearing voices or seeing visions by reducing self- stigma and developing a recovery oriented approach to coping with symptoms of hearing voices or seeing visions.

CHAPTER TWO:

ENGAGEMENT

Introduction

This chapter details the research plan for engagement with a peer support group centered on coping with hallucinatory experiences. The study site is described, including the group members, employees, and overarching organization. Engagement strategies for gatekeepers and prospective research participants are detailed. Plans for the researcher to prepare for data collection are detailed. Diversity, ethics, and politics are explored, and the role of technology is discussed.

Research Site

Participants in this research were recruited from a support group for hallucinatory experiences that is hosted by a local wellness center. The wellness center is part of a regional non-profit organization that serves two California counties, focusing on a range of mental health and housing services. The researcher is an employee of the nonprofit organization but is not an employee of the wellness center.

The support group is hosted in a wellness center that has a home-like atmosphere where multiple groups focused on mental wellness, recovery, and socialization are provided to the community free of charge. The wellness center refers to people who attend their groups as "members," and members must be

18 years or older and must sign confidentiality and wellness center guideline

paperwork before joining and attending groups. Participation of groups is

voluntary, but wellness center staff report that a small minority of members are

enrolled in forensic conditional release programs and are required to attend

groups.

<p align="center">Engagement Strategies for Gatekeepers at Research Site</p>

The gatekeepers at this research site included: the group facilitator, the

wellness center supervisor, and members of upper management of the non-profit

that provides the wellness center to the community. Ensuring that gatekeepers at

all levels trusted the research methods and research aims was essential in order

to carry out the research. Collaboration with gatekeepers at the wellness center

was needed in order to set up research interviews, and written approval from

upper management was needed for institutional review board (IRB) approval.

The researcher reached out to gatekeepers by phone and engaged in

conversation to find mutual ground concerning the values and aims of this

research project. After receiving affirmative feedback, the researcher provided

gatekeepers with a detailed description of the research methods via email and

invited feedback about any concerns. Email was used to keep track of progress

and address concerns as upper management at the nonprofit consulted with

each other before granting a letter for the IRB endorsing the research.

Self-Preparation

In order to properly conduct this research, the researcher sought to develop a solid understanding of the mental health challenges that members of research site support group face. A literature review was conducted in order to help the researcher understand: common challenges that people with these symptoms face, common treatments and therapeutic interventions support group members may have encountered in the past, etiquette that is commonly found to be affirming or helpful when discussing these issues, and common biases that members of this support group may face. This preparatory work was done to ensure the researcher upheld the ethical principles of social work.

The researcher took care to be sensitive to stigma surrounding this set of symptoms and engaged in preliminary conversations with gatekeepers to learn about building credibility and trust with the research participants (Kvrgic et al., 2013). Strategies to remain sensitive to issues of diversity are detailed in the diversity issues section below. The researcher prepared for interviews by developing broad launching points for topics to discuss. Open ended conversation topics were sought out centering around: group member's perception of stigma surrounding their symptoms, distress associated with their symptoms, their perception of how functionally impaired they are by their symptoms, and their general relationship with the support group. Care was taken to ensure that members of the group would have the opportunity to define terms for themselves and guide the research to areas relevant to them.

Diversity Issues

Preliminary contact with the research site revealed that the support group consists of a diverse membership. The group has had representation from Black, Latinx, white, and Asian ethnicities. The age range of members has spanned from the early twenties to the late sixties. Both men and women attend. Groups have historically skewed slightly male in composition. Although representation from the LGBTQIA+ community has been increasing, there has been a historical lack of LGBTQIA+ members.

A diversity issue which arose was engaging with all members of the group in culturally appropriate ways. Morris (2013) recommends adapting speech patterns, body language, and levels of eye contact to reflect the cultural norms of study participants. Awareness of historical factors surrounding various groups as well as internal biases of the researchers were held in mind while engaging with study participants.

Another diversity issue was the issue of mental health diversity. People who experience auditory or visual hallucinations are a minority population. They are a population who often remains unseen due to the fact that symptoms are often hidden due to stigma, as public depictions and descriptions of voice hearers are often laced with fear and judgement (Kvrgic et al., 2013). Goals of peer support groups include normalizing these experiences and educating voice hearers and non-voice hearers alike about the prevalence of these experiences. The researcher sought to uphold the group's cultural values and partner with

members in normalizing their experiences out of respect for their unique diversity.

Ethical Issues

Primary ethical issues which arose in this research were the needs for informed consent and confidentiality. Morris (2013) notes that post positivist research has the benefit of more time to identify potential ethical concerns while the initial research focus is being developed. Space for relevant ethical concerns to surface was allowed during the engagement phase with research participants. The researcher invited dialogue with prospective participants via e-mail to allow the research to take shape collaboratively.

Informed consent was sought from research participants at every stage of the process. Participants were kept informed about the intended subject of the interview as well as the intended length of the interview before being asked to consent to the interview. A detailed informed consent document was presented to participants via e-mail prior to research interviews, and the informed consent document was reviewed directly before research interviews took place (see Appendix C for consent form). Verbal consent for anonymous participation in the research was obtained by all participants. Participants were assured that participation was completely voluntary and were invited to discontinue at any time.

Care was taken to make sure that study participants and research respondent's names were not made publicly available. Names of study

participants, along with identifying information, were kept anonymous. Participants were reminded not to include any identifying information (for themselves or others) before research interviews. Even so, recordings and transcripts were kept password protected so that confidentiality would be ensured. Recruitment flyers (see Appendix D) were distributed to support group members via physical copies and email copies by staff of the wellness center that hosts the group; flyers were not distributed to prospective participants by the researcher. Interested parties contacted the researcher at an email address provided by the nonprofit organization that hosts the support group.

An important secondary issue that arose with this study is the experience of stigma for study participants and the possibility of psychological or emotional harm inflicted on study participants during the process. In addition to his personal research, the researcher engaged in conversations with wellness center staff to learn about group culture and raise awareness about language or actions which would be triggering or offensive. The researcher also consulted with two licensed therapists who have experience serving this population to gain knowledge about stigma and proper etiquette surrounding this population. Finally, perspectives and preferences of study participants were sought out and respected as the study was carried out.

<center>Political Issues</center>

No major political issues arose with the support group or with the hosting nonprofit. These entities share common values with the researcher of respecting

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clients, upholding confidentiality, and operating from a strengths-based perspective. These ideals align well with the post-positivist research approach chosen for this work. The researcher assured gatekeepers that group members would be treated as experts to be learned from, with the goal of gaining mutual insight as themes and lessons emerge from the interview process. The utmost care was taken to ensure that clients were treated with respect and that their confidentiality was maintained.

Establishing affable and respectful relationships is an important component of the engagement process (Morris, 2013). Minor political issues with relevant parties were expected to arise revolving around: the potential impact that the requests of the research project could have on the group members, the functioning of the group, and the time commitment involved with research participation. Although efforts were taken to avoid unclear communication or burdensome coordination demands, mutuality was displayed between the researcher, gatekeepers, and research participants in coordinating the research. The researcher offered heartfelt thanks to all parties.

COVID-19 and The Role of Technology

The COVID-19 pandemic necessitated the use of technology for communication between individuals and groups due to the risk of spreading the disease. Many of the wellness center's groups have been meeting virtually via Zoom since quarantines were mandated by the California State Government in March of 2020. The hallucinations support group chose to suspend meetings

until they could meet in person, due to low attendance when offered via Zoom. Wellness center staff reported that a high proportion of group members found videoconferencing uncomfortable because of how it interacted with their symptoms. Members of the support group shared that it was more difficult to distinguish between speech spoken by a group member and speech spoken their auditory hallucinations when attending group via Zoom. The group resumed meeting in person in 2022, with COVID precautions such as COVID symptom checks, masking, and distancing.

The researcher faced a dilemma when planning the format for research interviews- should interviews be held via Zoom to ensure COVID safety, or should interviews be held in person to honor the preferences of group members. The dilemma was resolved by giving research participants choice of either interview format while taking all necessary COVID precautions should interviews be offered in person. It is important to establish comfort and rapport with research participants so that the post positivist data gathering approach can be properly carried out (Morris, 2013). All participants chose to be interviewed in person in a confidential space provided by the wellness center.

<p style="text-align:center">Summary</p>

The study site was described as a support group for hallucinations hosted at a wellness center overseen by a nonprofit mental health organization. Strategies, plans, and considerations for engagement with gatekeepers were detailed. Self-preparation, diversity issues, ethical issues, and political issues

were explored, especially as these categories related to successful engagement and implementation of the research. Finally, COVID-19 and the role of technology as they intersected with the support group were discussed.

CHAPTER THREE:

IMPLEMENTATION

Introduction

This chapter details the plan for implementing the research study. The

population of the study participants is summarized along with the plan for

selecting and recruiting study participants. The plan for data collection, along with

how each phase of the data collection process was approached, is explained.

Plans and considerations about the method of data recording are offered.

Chapter three ends with sections which detail data analysis and ongoing steps

for successful termination and follow up.

Selection of Participants

This study sought to discover how participation in peer support groups can

lead to quality-of-life improvements for individuals who hear voices or see

visions. The sampling strategy employed was the typical case sampling strategy;

data from the sample provides a representative picture of the experiences of

those within the sample (Morris, 2013). A deeper understanding of how, and why,

support groups are helpful for those who hear voices and see visions was sought

so an invitation to all members of the support group to participate in the research

project is most appropriate. Members who were experiencing benefits from the

group were the most likely, and able, to participate. Other sampling strategies

which select for specific characteristics within a population were not appropriate

because the population of hallucinatory symptom focused support groups has not been adequately studied.

Participation in the study was limited to support group members who have established active participation in the group. The researcher allowed group members and wellness center staff to define what it meant to be active in the group. Several prospective study participants (separately) reached a mutual decision with the researcher or wellness center staff to not participate in the study because their involvement with the group was too transient to reliably provide data in accordance with the aims of the study. There was one active group member who planned on participating in the study who canceled their planned research interview due to an increase in mental health symptoms during that period.

The researcher offered recruitment materials to wellness center staff and the leader of the group (see Appendix D) along with invitations for potential participants to contact the researcher via e-mail with any questions. Self-selection within the group took place as to who participated in the study. While inviting participants the researcher highlighted empowering aspects of the study, acknowledging that group members are doing important support work and that the insights of group members are needed to guide this research may help increase understanding about the benefits of their support group.

Data Collection

Being rooted in the post-positivist research paradigm, the study was guided by the belief that there are discoverable, objective truths about psychology and sociology related to support groups. A naturalist approach to data collecting was employed. Morris (2014) shares that this approach is optimal for post positivist research because rigorous qualitative analysis can be applied to observations while minimizing tainting of the data from biases or preconceived notions of the researcher. Although a case-study structure with the researcher directly observing support group sessions in action may have better provided a naturalistic research setting, observation was not optimal because this research sought to ascertain participant's perceptions of how the group benefits them- internal information that would not likely be shared during a support group session. Direct communication needed to be established in a way that offered participants the time and emotional space to explore, share and dialogue with the researcher.

Research Interviews

Data was gathered by conducting one-on-one interviews with research participants. The researcher allowed participants to choose between meeting virtually via Zoom video conference software or meeting in person in a confidential space at the wellness center based on which arrangement was most comfortable for them. All four participants chose to meet in-person. Research was conducted with one in-depth interview per participant.

All participants were offered the same set of research questions (see Appendix B). Interviews consisted of 17 questions: 1 question seeking information about the participant's baseline, 1 asking about demographics, 8 open ended questions about different aspects of group participation, 2 questions directly inquiring about alleviating distress, 2 questions directly inquiring about stigma, 2 questions directly inquiring about impairment, and 1 question asking participants for feedback about the interview. The researcher engaged participants with probing and clarifying questions while gathering data for each research question, allowing participants to guide the conversation to areas important to them. Interviewees were thanked for their participation.

The researcher estimated that interviews would last 20 minutes and stated as such on recruitment materials. The lengths of the four interviews ranged from 21 minutes to 39 minutes, with the average length being 32 minutes. Time spent discussing the consent form (see Appendix C) and obtaining verbal consent was not counted towards interview length.

Data Recording

The researcher made efforts to capture participant's exact wording, along with the conversational context of their responses. Zoom software on the researcher's password secured, CSUSB issued iPad was used to make audio recordings of interviews. These procedures were discussed both in advance of the research interviews and directly before the interviews by utilizing the informed consent document (see Appendix C) and obtaining verbal consent to participate

in this anonymous research. Zoom software was used to generate a textual transcription of interview content. After each interview was completed, time was taken to compare the textual transcription to the audio recording to ensure accuracy.

One participant expressed strong discomfort regarding being recorded. The researcher's advisor was consulted regarding this request and an alternate method was devised. The researcher took detailed written notes by hand during the interview with this participant and immediately after the interview typed up the transcript of responses while striving for maximum accuracy for wording of the participant's responses. The participant and researcher collaborated during the interview to balance pauses so the researcher had time to write notes with allowing the participant freedom to fully express their responses.

<div align="center">Data Analysis Procedures</div>

The units of analysis in this study are the transcript data containing information from participants about ways group participation lead to quality-of-life improvements for participants. In this context thematic analysis is an optimum qualitative research method to examine these units of analysis (Braun & Clarke, 2006). Participant's responses were investigated in order to produce major themes. Care has been taken in the writing of this section to clearly explain the steps taken in the thematic analysis because ambiguity regarding the qualitative analysis process is a common weakness of qualitative studies (Belotto, 2018).

The researcher started by familiarizing himself with each transcript. Braun & Clarke (2006) share that this is important because later stages of thematic analysis rely on the researcher understanding the relationships between codes, themes, and the data. The researcher then prepared a large table in Microsoft Word for coding the data. On the left the table contained interview questions with the participant's responses in the four boxes below. The researcher's half of the conversation was removed from the transcript at this point, but the researchers' words were kept intact in the individual interview transcripts if need for context arose. 1212 lines of textual data were assembled in this table (not including the research questions).

The researcher read through the code table and assigned initial codes in the right column to lines of data in the left column. Codes in column on the right side of table allowed codes to remain linked to the appropriate line of transcript data. Initial coding yielded 63 initial codes. 685 of the 1212 lines of textual data were assigned codes summarizing meaning- approximately 1 code for every 2 lines of transcript data.

Level 1 coding condensed the 63 initial codes to 24 unique codes (see Appendix A). No initial codes were deleted. Initial codes with similar meanings were combined. Some level 1 codes appeared very similar due to featuring similar wording but were left separate due to different contextual meaning. For example, "finding courage to share" described different data than "more comfortable sharing." "Finding courage to share" applied when participants

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detailed the process of choosing to open up about their hallucinations while attending the group, but "more comfortable sharing" was used as a code when participants indicated that group participation has made disclosing their experiences more comfortable in general contexts or that participants foresaw disclosure becoming more comfortable in the future.

The researcher printed out the finalized list of level 1 codes and cut them into physical strips that could be rearranged. Level 2 coding was conducted via a mind mapping exercise. Level 1 codes were grouped and rearranged on a large paper while notes were written and lines were drawn to identify relationships between codes. This exercise produced 8 themes describing the benefits of group participation (see Appendix A, see Emerged Themes in Chapter Four).

The researcher sought to add a quantitative element to the level 1 and level 2 data to determine what proportion of the data codes and themes represented. This was accomplished in three ways. First the researcher examined the data to determine what proportion of the four participants had each code assigned to their transcript at least once. This was done to ensure that codes didn't make it into the data because of a vocal minority. Second the number of instances of each code were totaled so that the proportion of individual codes could be compared to the 685 total codes ascribed to the 1212 total lines of data. Third the number of instances that all codes under each theme appeared were added together and then divided by the 1212 lines of data. This offered the prevalence of that theme in the data set as a percentage of the total

lines. A table was constructed to clearly display the data and analysis (see Appendix A: Codes Themes and Prevalence).

Termination and Follow Up

The researcher thanked each participant for their time and contributions after their interview concluded. The interview process was contemplative, exploratory, and connecting, so it was natural to leave opportunity for research participants to gain any closure or share any final insights if they desired. This was built into the final research question "would you like to share any feedback with me, about how you felt answering these questions or with how I've approached things?" Additionally the researcher chose to remain available so each participant could connect further should any desire arise to do so. Participants chatted briefly afterwards for five minutes or less and independently chose to leave. Upon departure all participants presented with a similar emotional and mental state compared to their baseline (established with the first interview question) and made positive remarks about the interview process.

A summary of findings will be assembled and submitted to the support group that provided participants for the study. The document currently being read would not be a suitable medium to convey research findings to support group members and wellness center employees. Instead, a pamphlet will be assembled which details the findings of the study along with proposed applications. This pamphlet will be sent in the form of a digital file so that group members and wellness center staff can share it digitally or print it. The pamphlet can serve as

an aid to the group to encourage practices that members find beneficial and can also be used as an outreach tool because the pamphlet would detail the strengths and benefits of support groups centered around these symptoms. Stakeholders at the research site have expressed eagerness to obtain said summary pamphlet.

Summary

Chapter three detailed the collaborative process of conducting research interviews with members of a local peer support group centered around hallucinatory experiences. The researcher's process of applying thematic analysis to the research data was explained. The researcher organized and familiarized himself with the textual data from research interviews. Data was organized so that extensive coding and analysis could be applied. Codes were organized and themes illuminating how the group benefits members were derived from the data. An element of quantitative analysis was added to illuminate what proportion of the data each code and theme represented (see Appendix A: Codes Themes and Prevalence). Efforts for respectful termination of research participation were detailed.

CHAPTER FOUR:

RESULTS

Introduction

Four interviews with members of a peer support group for experiences of audio and visual hallucinations yielded 128 minutes of interview data. Textual transcripts of participant's responses were developed, with the units of analysis composed of group members' words and none the researcher's words. Thematic analysis of this 1212 line long data set yielded 24 level 1 codes (from 63 initial) codes. Level 1 codes described 685 of the 1212 lines of data in the set. Of the 24 level 1 codes, 10 were attributed to three of the four participants at least once, while the other 14 codes were attributed to every participant at least once. Eight themes describing benefits of peer support groups for this population were derived from the 24 level 1 codes, and the prevalence of each theme in the data set was calculated (see Appendix A: Codes Themes and Prevalence).

Demographic Characteristics

The ages of participants ranged from 29 to 60 with an average age of 42. Three males (including one transgender male) and one female took part in the study. English was the primary language of all participants. The majority of participants were white and one participant identified as Black and Central American. All participants had completed some college; one holds a bachelor's degree and another holds an associate's degree. One participant was not employed at the time of the study while two were employed part-time and one

was employed full-time. All participants were single with one sharing that they were divorced.

Clinical Characteristics

All participants disclosed that they have been diagnosed with mental illness, and all participants endorsed their diagnoses. Two participants named schizophrenia as their primary diagnosis, one participant named bipolar disorder as their primary diagnosis, and one participant did not share their primary diagnosis while indicating that it was not schizophrenia. Three of four participants disclosed hearing auditory hallucinations on a daily basis with the fourth sharing that auditory hallucinations occur during periods of high stress. Two participants endorsed visual hallucinations, with one indicating a low to moderate frequency and the other describing persistent daily visual hallucinations. One participant requested that the study include mention that hallucinations occur in other senses beyond hearing and sight, and that they have personally had such experiences.

Emergent Themes

Analysis identified eight themes. All participants offered significant research data to support each theme.

Theme 1. Group Provides a Safe Space

Members of the support group were drawn to attend because they desired an environment where other people who experience hallucinations will offer

psychological safety and an assurance that they, and their hallucinations, are welcome. One participant stated, "I had never really spoken with another person with similar experiences until I first went to the group" and said later in the interview "I had gone 18 years without talking about it." Another participant said "I had not been able to find much support for voice hearers, and had never been anywhere else where we've been able to share about experiences like hearing voices… my initial reaction was excitement."

The code within this theme that had the highest prevalence was that the support group offered members a sense of safety is unique in comparison to other contexts. One participant frequently contrasted the positive experience of being in group against how "things are out in the real world." The second most prevalent code within the theme showed that participants trust other group members to be considerate and kind. 4.6% of all data gathered from participants is attributable to this theme. While it was the seventh most prevalent theme of the eight, interview participants frequently connected other benefits to this theme.

Theme 2. Growth in Communication Skills

A major theme found in the data was that group participation helped members develop communication skills that were beneficial to them outside of the group context. One participant said "another thing this group has helped me with is that I'm a bit more apt to talk to therapists. The group has helped me be more open." Another participant said, "In the beginning (of my group attendance) I was just an observer, just listening rather than participating… but now I'm not

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hiding it as much and I even told my case manager when my (hallucinatory) vision was giving me a bad day."

Codes within this theme centered around different aspects of providing supportive listening to other group members and taking opportunities to "no longer hide" or "express honestly." 7.4% of all data gathered from participants is attributable to this theme, it was the fourth most prevalent theme of the eight.

Theme 3. Group Meets Belongingness Needs

Participants frequently returned to the idea that the peer support group offers a sense of belonging and trust. This theme is related to the first theme, that the group provides a safe space, but the fact that the group provides a sense of community and meets a need for belonging merited distinction as a unique theme. A string of dialogue from one participant illuminates how the group offers support on a deeper level than theme 1, "I had to keep that in for almost 45 years of my life. I was not able to express my symptoms, but now I know I can meet people like me and I'm not alone… we feel safe and can trust each other… we have to protect that."

The code in this category that occurred most commonly indicated that group participation generally coincides with building trust. The second and third most common codes in this category described moving from being isolated towards being connected to others and experiencing emotional safety in the group context. 11.8% of all data gathered from participants is attributable to this

theme. It was the most prevalent theme of the eight, suggesting that this theme was the most salient in the minds of research participants.

Theme 4. Participation Increases Euthymia

The fourth theme that emerged from that data was that group participation is associated with increased stability of mood and a more steady interaction with others in the social environment. This increase in euthymia was most often described as a within-day benefit that came with group attendance. One research participant said, "that sense of understanding…has been really beneficial for me a lot of times when I'm symptomatic… just having someone nod and day they've experienced that, it calms me." Another research participant shared their observation of other group members, "there are times when people check in at the beginning really in distress, and then, when they check out (at the end of group) they're like 'I feel so much better!'"

The most prevalent codes in this category described how the sense of connection within the group lowered symptoms while increasing a sense of self-regulation as well as descriptions of "feeling good" or "feeling better" from group participation. 5.1% of all data gathered from participants is attributable to this theme, it was the sixth most prevalent theme of the eight.

Theme 5. Increased Ability to Cope

Research participants frequently shared about ways that the peer support group increased their ability to cope with challenging symptoms. One participant said "the handouts and the videos, and also the coping skills we get from group,

they really help… the others will get all excited if you share you couldn't get out of bed one day but then used a coping skill to get through it." An example of how new insight and perspectives from the group increased a member's ability to cope was when they shared "I had a hard time at first, realizing that not everybody has the same voices. Not everyone has the same feeling or even reactions. Some might have one voice some might have many. It helped me see mine different."

Codes under this theme were tightly related to each other. Participants shared both about learning new coping skills and also brainstorming with the group about how to implement coping skills. Having confidence in coping skills increased ability to cope daily with the stress and anxiety that come from experiencing hallucinations, the content of which were reported to be disturbing or discouraging at times. 10.8% of all data gathered from participants is attributable to this theme, it was the second most prevalent theme of the eight.

Theme 6. Normalization of Audio and Visual Hallucinations

A common theme that came forth in the research interviews was that group participation helped to normalize hallucinations. One participant said "a lot of my peer's experience is rooted in shame" and elaborated by sharing that group participation seems to help people feel less ashamed of what they experience. Research participants frequently used phrases such as "they're like me," "being honest" and "being seen," Every research participant stated that they intentionally disclose their hallucinatory symptoms in the group context in the

hope that they can normalize experiences for other group members and assist others in enjoying the benefits of previously described themes.

Code content in this category, where participants described sharing about hallucinations and not feeling rejected, or experiencing validation or affirmation, were associated with themes of self-acceptance and heightened social confidence. 7.6% of all data gathered from participants is attributable to this theme, it was the third most prevalent theme of the eight.

Theme 7. Addressing Stigma

Three out of four research participants stated that combating societal stigma that surrounds hallucinations is a primary reason they attend the group. One participant shared "Most of the stigma is outside the group, I haven't observed a ton of self-stigma in the group… stigma is hard to deal with." Participants described how the group takes time to process societal stigma regarding hallucinations that members observe outside of group, and also how the group seeks to disconfirm stereotypes.

3.8% of all data gathered from participants is attributable to this theme, it was the least prevalent theme of the eight. However, the prevalence calculation for this theme is misleading because, more than any other emergent theme, the "addressing stigma" theme connected with other themes when the topic was discussed in interviews. For example one member jumped straight from the theme of stigma to the theme that the group provides a safe space, saying "to

fight stigma, just being nice, polite, cheerful, and giving them your good advice…

they can be supported by people who go through the same thing."

Theme 8. Group Participation Increases Hope

The final theme that was found in the interview data was that participation

in the group comes with a sense of hope; members believe that together they

can bring about positive change in their own lives and perhaps bring positive

change to society. One member said "I've learned to really take in the days when

we can just be okay, and now I expect them more." Another member said "seeing

other people's accomplishments brings more optimism. It's like an upward circle.

We all see how the group support is helping and we all get encouraged."

The most frequently occurring code within this theme centered around the

idea of discovering new possibilities. Members of the group celebrate when

others find new ways of coping, obtain a part time job, or find new sources of

meaning in life. Other prevalent codes described member's belief that the group

is helpful, and how members become inspired and hopeful as they observe peers

become more comfortable sharing honestly. 5.9% of all data gathered from

participants is attributable to this theme, it was the fifth most prevalent theme of

the eight.

<div align="center">Summary</div>

Interviews exploring the benefits of support group participation were

conducted with four group members who live with hallucinatory experiences.

Benefits in eight thematic domains were identified. Participants reported that the

<div align="center">37</div>

group: provided a safe space, facilitated growth in communication skills, met

needs for belongingness and emotional safety, increased euthymia, increased

ability to cope with challenging symptoms, assisted in normalizing hallucination

experiences, addressed perceptions of stigma surrounding hearing voices or

seeing visions, and that being involved in the group led to increased hopefulness.

CHAPTER FIVE:

DISCUSSION

Introduction

This qualitative study explored the benefits of support groups for individuals living with hallucinatory experiences. Research data revealed that group participation came with benefits in more thematic areas than the researcher expected. These findings suggest that there are rich and interconnected benefits offered by peer support groups that focus on providing support for people who experience hallucinations. Although participants often enter a support group with the intention of normalizing their experiences, continued participation appears to be associated with significantly more benefits than anticipated.

Findings

The eight research themes identified by this study (see Appendix A) appear to work synergistically to enhance the lives of members of the peer support group for hallucinations. A general progression appears to take place where peer-support group members experience sequential benefits, progressing through the eight identified themes. For example, a new member begins to share more frequently in the group as they realize that it truly is a safe environment, thus growing their communication skills and sense of belonging. The member

then begins to experience greater euthymia while in group and their confidence in utilizing coping skills such as mindfulness or self-compassion increases. With increased functioning and lowered levels of distress, along with a deepening sense of camaraderie, the member can address stigma as their experiences become more normalized in their mind. Positive experiences during group, along with increased quality of life, lead to the member internalizing the sense of hope that other group members share. Themes of hope are reinforced by success stories shared during group sessions. The eight themes that resulted in this qualitative analysis were numbered from one to eight with this sequential observation in mind.

Three domains for possible benefit were identified while formulating this research, the domains of distress reduction, increased functioning, and decreased stigma. Data provided by research participants indicate that group participation yields improvement in all three areas of interest. Distress reduction was reported in association with psychological and emotional safety provided to members by the group, increased ability to cope with anxiety and hallucinations, and more ease achieving euthymia by co-regulating with peers. Increased functioning was not noted as strongly as benefits in the other research focus areas, but participants reported working jobs and achievements such as getting out of bed on a day they wouldn't have been able to prior to group support. The group shares a value for addressing stigma and brainstorming ways to both

reduce societal stigma regarding hallucinations and creating an environment of acceptance for all group participants.

The nature of this research was purposefully exploratory because more research needs to be conducted on the benefits of the peer-support model for people who experience audio, visual, or other hallucinations. Although this research indicated strong and varied benefits from peer-support group participation, Lloyd-Evans et al. (2014) argued that there is little evidence that peer support groups or peer support services increase beneficial outcomes for clients with severe mental illness. Lloyd-Evans et al. (2014) conducted a meta-analysis and systematic review of trials of peer support for people with severe mental illness. Although none of the studies they reviewed focused exclusively on hallucinations, the researchers only included studies whose participants were diagnosed with schizophrenia or bipolar disorders (the two diagnoses shared by the participants in this project). Although numerous benefits of peer support were identified among the participants in this project, Lloyd-Evans et al. (2014) begs the question of whether the beneficial themes identified in this study would induce measurable long-term gains in psychosocial functioning.

The optimistic findings of this study lend strength to the claims by Kvrgic et al. (2012) that recovery orientation, reduction of self-stigma, and increased insight are beneficial for people who experience hallucinations. Although Kvrgic et al. (2012) discussed the role of these factors with the diagnosis of schizophrenia, and not in association with the experiences of hallucinations as

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did this project, a comparison can be made given the prevalence of schizophrenia diagnosis in this project's sample along with the lack of research focused on hallucinations themselves as a variable. This project's themes of growth (in communication skills, ability to cope, and ease of achieving euthymia) map well to Kvrgic et al.'s (2012) descriptions of growth in insight and therapeutic alliance throughout recovery. This project's themes of belonging, addressing stigma, and increasing hope are similar to Kvrgic et al.'s (2012) focus on therapeutic alliance, self-stigma reduction, and recovery orientation. It appears likely that a well-run peer-support group for hallucinatory experiences can provide many of the beneficial factors that therapists specializing in schizophrenia treatment provide.

<center>Limitations</center>

This study's low sample size limits generalizability of the findings. Further, all participants of this study were from one support group. Recruitment of participants from multiple, diverse, sites would have increased the certainty and applicability of the findings of the study as they relate to hallucination-focused support groups nationwide and worldwide. This study also did not explore possible limitations of the peer support approach that may arise due to danger in forensic psychiatric populations. However, it was necessary to limit the scope of this work due to the difficulties which would arise from negotiating with gatekeepers at multiple support group sites- exponentially increasing the amount

of data to be collected. Lastly coding in this study was done solely by the main author without measures taken for inter-rater reliability.

The impact of personal bias, on the part of the researcher and the participants, must be explored in light of the post-positivist research paradigm employed in this project. The research findings describe the perceptions of support group members and may not accurately describe reality. Further, this researcher engaged participants with his own preconceived notion that benefits of the group were there to be found. Lloyd-Evans et al. (2014) reported that there is a high risk of bias in studies examining benefits of peer support. Future research should investigate the eight beneficial themes identified in this study with greater efforts to recognize, and work with, biases surrounding this research topic.

Conclusion

Every participant in this research study offered significant data in support of each of the eight identified themes, suggesting that the themes identified in this study may be universal benefits of peer support groups for hallucinations. Participants shared how they kept their auditory and/or visual hallucinations secret for years, sometimes even while attending other mental health services. Participants also detailed how consistent participation in the peer support group was associated with benefits in a range of domains. Members of the social work and psychology professions should make efforts to identify peer support

resources for clients who experience hallucinations. Practitioners are invited re-examine possible personal biases they may hold toward clients who experience audio or visual hallucinations and reconsider the medication-first model that is prevalent today.

Future studies should develop protocols to ensure inter-rater reliability to improve the trustworthiness of the coding and interpretation of the data (Belotto, 2018). Although this researcher was intentional in preserving the clarity of participant's responses and being unbiased in coding and thematic analysis, collaboration with others while carrying out these processes would lend further credibility to the findings.

Studies utilizing larger sample sizes, while also recruiting diverse participants from multiple locations, are needed to determine whether the benefits in this study are unique to this local support group or to this sample of four participants. Work needs to be done to understand and operationalize beneficial peer-support themes and factors for groups serving this population. Standardized measures would lend clarity and certainty to the findings of this study while also providing the opportunity to assess and compare the quality of hallucination-focused peer-support groups.

APPENDIX A:

CODES THEMES AND PREVALENCE

Codes (Level 1) (applied to 1212 lines of data)	Number of Instances (685 total)	Reported by how many?	Themes (Level 2)	Prevalence Of Theme in Data Set
Sought safe space	7	4 of 4		
Invited by others	5	3 of 4	Group provides a safe space	4.6%
Consideration of others	19	4 of 4		
Look forward to group	4	3 of 4		
Group offers unique safety	21	4 of 4		
Supportive listening	21	4 of 4		
Finding courage to share	16	4 of 4	Growth in Communication Skills	7.4%
Self-expression	16	4 of 4		
No longer hiding	18	4 of 4		
Freedom to process honestly	18	4 of 4		
Building trust	26	4 of 4		
Meeting people like myself	10	4 of 4		
Camaraderie	18	4 of 4	Group meets belongingness needs	11.8%
Built on established support	8	3 of 4		
Emotional safety in group	20	4 of 4		
Isolation to connection	21	4 of 4		
Belonging in community	15	3 of 4		
Feeling less alone	23	4 of 4		
Connection lowers symptoms	21	4 of 4		
Present in moment	9	3 of 4	Participation increases euthymia	5.1%
Felt good	17	4 of 4		
Not bound by AH/VH	8	3 of 4		
Leave feeling better	6	4 of 4		
Learning coping skills	19	4 of 4		
New insight and perspectives	25	4 of 4		
Empowering each other	14	4 of 4		
Brainstorming use of coping	16	4 of 4	Increased ability to cope	10.8%
Overcoming stress/anxiety	22	4 of 4		
General resiliency	11	4 of 4		
Group helps identify strengths	5	3 of 4		
Daily coping with AH/VH	18	4 of 4		
Being validated	24	4 of 4		
I have AH/VH- not rejected	19	3 of 4	Normalization of AH/VH	7.6%
Their experiences- like mine	19	4 of 4		
Being seen and affirmed	29	4 of 4		
Disconfirming stereotypes	12	3 of 4		
Affirmation replacing stigma	10	4 of 4	Addressing stigma	3.8%
Solidarity in rejecting stigma	6	3 of 4		
Processing societal stigma	18	4 of 4		
New possibilities	27	4 of 4		
Belief that group is helpful	12	4 of 4	Group participation increases hope	5.9%
Increased wellness over time	10	4 of 4		
More comfortable sharing	15	4 of 4		
Life satisfaction	7	4 of 4		

APPENDIX B:

RESEARCH QUESTIONS

School of Social Work

CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO
5500 University Parkway, San Bernardino, CA 92407
909.537.5501 | fax: 909.537.7029
http://socialwork.csusb.edu

Benefits of Peer Support Groups for Voices and Visions - Research Survey
(Joe Stewart, California State University San Bernardino Master of Social Work candidate)

Review informed consent document and obtain verbal consent

1. How has your day been going and how are you feeling now?

2. Confidential General Demographic Information:
   a. Age -
   b. Gender -
   c. Race/Ethnicity -
   d. English Primary Language? -
   e. Highest Education Level Completed -
   f. Employment Status -
   g. Relationship Status -

3. How did you come to find the Voices and Visions support group?

4. What were you looking for from the group when you decided to attend?

5. What was it like for you when you first started attending the group?

6. How is it for you to attend the group nowadays? I'm interested in learning about how it feels and if there is a sense of community.

7. Are there any ways that you offer a sense of community, or empowerment, to others in the group? The more descriptive, the better.

8. How do you respond to the personal shares from other group members (please remember not to use any identifying information).

9. Could you share about what you feel attending the group brings into your life? I'm curious about how it is for you to attend the group and to have that camaraderie.

10. Some people feel a stigma about hearing voices or seeing visions. Has being a part of this group counteracted stigma for you in any ways? Please explain

11. When it comes to stigma, what does it look like for you to provide support to other group members?

12. Some people share that their voices or visions sometimes make them feel uncomfortable. Could you share about any ways being a part of the group has shifted any feelings of stress or discomfort for you.

13. Are there times you've observed that group support has improved feelings of discomfort for other people in the group? Please explain.

14. Some people share that their voices or visions get in the way of them accomplishing the things they want. If your voices or visions have ever held you back, I'm curious if being a part of the group has helped you to accomplish more of the things you've wanted to do.

15. Are there ways that you have supported other group members to accomplish more of the things they want to?

16. Is there anything that you would like to add? You're the subject matter expert here, so I might not have asked all the right questions.

17. Would you like to share any feedback with me, about how you felt answering these questions or with how I've approached things?

APPENDIX C:

INFORMED CONSENT

CSUSB

WE DEFINE THE *future*

School of Social Work

CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO
5500 University Parkway, San Bernardino, CA 92407
909.537.5501 | fax: 909.537.7029
http://socialwork.csusb.edu

Informed Consent for Research Participation

The study in which you are being asked to participate is designed to investigate how support groups are beneficial for people who hear voices and/or see visions. This study is being conducted by Joseph Stewart (CSUSB Master of Social Work Student) under the supervision of Dr. Caroline Lim (CSUSB School of Social Work Assistant Professor). This study has been approved by the Institutional Review Board, California State University, San Bernardino.

Purpose: The purpose of this research study is to explore how peer support groups are beneficial for people who experience auditory and/or visual hallucinations. The research format is conversational, with open ended questions because this research is exploratory. Perspectives and ideas are invited.

Description: Participants of this research study will engage in an anonymous, audio recorded interview about the benefits of support groups for people who have experienced hallucinations. All participants will be asked the same set of questions. Interviews will be approximately 20 minutes. After all interviews are conducted the researcher will analyze the contents of the interviews to find important themes.

Participation: Your participation is completely voluntary and you do not have to answer any questions you do not wish to answer. You may skip or not answer any questions and can freely withdraw from participation at any time.

Anonymous: Participation in this research is anonymous. Your name and personal information will not be included in the published result of this research, and you are asked not to share your name or identifying information during the recorded interview. Your responses collected in interviews will be presented in group format. This informed consent document will remain confidential and secure; it will be destroyed within 3 years of completion of this research.

Duration: Research participation will take about 20 minutes of your time; only one research interview is requested. Participation is voluntary and can be suspended or discontinued at any time.

Risks: No risks of participation are expected. Participation may touch on personal subjects, which may bring up discomfort. Participation is voluntary. You can skip questions or discontinue participation at any time. Although efforts are being taken to ensure your anonymity, there is a risk that you may be identified in the case of a breach of research protocol. Research data will be anonymous, and this informed consent document will be kept securely confidential.

Benefits: The Voices and Visions support group will be provided with a pamphlet summarizing the results when the research is finished. Participation in this research may bring you: increased levels of personal insight, increased motivation to participate in the Voices and Visions group, and a sense of affirmation from contributing to social work knowledge through your participation.

Audio: I understand that this research will include an (anonymous) recording of the interview.

Yes □ or No □

The California State University • Bakersfield • Channel Islands • Chico • Dominguez Hills • East Bay • Fresno • Fullerton • Humboldt • Long Beach • Los Angeles
Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • SAN BERNARDINO • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus

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Contact: If I have any questions about this research, I understand that I am welcome to reach out. Joseph can be reached at jstewart@t-mha.org, and Joseph's research supervisor Dr. Lim can be reached at caroline.lim@csusb.edu

If I have any questions about my rights or treatment as a participant in this study, I can visit the US Office for Human Research Protections for more information https://www.hhs.gov/ohrp/. If I have concerns, I can contact the California State University San Bernardino research compliance officer at 909-537-7588.

Results: The researcher will provide a pamphlet summarizing the results of the research, to be available at the wellness center. If full presentation of research results are wished to be obtained, they can be obtained at:

https://scholarworks.lib.csusb.edu -> Disciplines -> College of Social and Behavioral Sciences School of Social Work ->Social Work Theses, Projects, and Dissertations -> year 2023.

Confirmation Statement: I understand that I must be 18 years of age or older to participate in your study, have read and understand the consent document, and agree to participate in your study.

I, _____, give my verbal consent to participate in this research study.

This study has been approved by the CSUSB Institutional Review Board (IRB). IRB-FY2022-187

APPENDIX D:

RECRUITMENT FLYER

People who experience voices and visions may find peer support groups very beneficial, but many professionals either don't know about this or don't understand.

Your voice can help shed light on the benefits of peer support groups by offering your anonymous participation in this research project.

The goal of this new research project is to learn more about how peer support groups are beneficial for folks who hear voices and/or see visions. To participate in the study, you just need to meet with master of social work student Joe Stewart for one confidential interview. In this quick, empowering interview (about 20 minutes) you will be asked open ended questions about what good happens when people participate in the group. There are no wrong answers. Once all the interviews are completed, responses will be analyzed to give a more complete picture of the group's benefits.

Why You Should Participate:
- This study will increase awareness and understanding within the Social Work profession of peer support groups for voices and visions.
- Results of this study may promote mental health care which is less stigmatizing.
- You may find participation to be an empowering experience; you are the expert here.
- Sharing may expand your personal insight into how group participation enhances your life.
- Lessons learned from the project will be shared with the Voices and Visions group upon completion in the form of a pamphlet that can be used to invite new members to the group.

Who Can Participate:
- Adults 18 years or older.
- Those who have experienced hearing voices and/or seeing visions.
- Those who have participated in the Hope House Voices and Visions group in the past year.
- Those able to commit to one anonymous, recorded interview with Joe. About 20 minutes.

To arrange a time to participate in this research, or to ask any questions, Please email MSW student Joe Stewart at: jstewart@t-mha.org

-Interviews available either via Zoom or in-person at the wellness center-
-Participation will be anonymous. Nothing in the published results will reveal information about you-
-Please let me know if you have any questions I can answer-

Thank you for considering participating

This study has been approved by the CSUSB Institutional Review Board (IRB). IRB-FY2022-187

APPENDIX E:

IRB APPROVAL LETTER

CALIFORNIA STATE UNIVERSITY
SAN BERNARDINO

May 2, 2023

CSUSB INSTITUTIONAL REVIEW BOARD
Protocol Change/Modification
IRB-FY2022-187
Status: Exempt

Caroline LimJoseph Stewart
CSBS - Social Work
California State University, San Bernardino
5500 University Parkway
San Bernardino, California 92407

Dear Caroline Lim Joseph Stewart:

The protocol change/modification to your application to use human subjects, titled "The benefits of support groups for individuals who experience auditory and visual hallucinations" has been reviewed and approved by the Chair of the Institutional Review Board (IRB), A change in your informed consent requires resubmission of your protocol as amended, Please ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study, A lapse in your approval may result in your not being able to use the data collected during the lapse in your approval.

This approval notice does not replace any departmental or additional campus approvals which may be required including access to CSUSB campus facilities and affiliate campuses. Investigators should consider the changing COVID-19 circumstances based on current CDC, California Department of Public Health, and campus guidance and submit appropriate protocol modifications to the IRB as needed. CSUSB campus and affiliate health screenings should be completed for all campus human research related activities, Human research activities conducted at off-campus sites should follow CDC, California Department of Public Health, and local guidance. See CSUSB's COVID-19 Prevention Plan for more information regarding campus requirements.

You are required to notify the IRB of the following by submitting the appropriate form (modification, unanticipated/adverse event, renewal, study closure) through the online Cayuse IRB Submission System.

1. If you need to make any changes/modifications to your protocol submit a modification form as the IRB must review all changes before implementing them in your study to ensure the degree of risk has not changed.
2. If any unanticipated adverse events are experienced by subjects during your research study or project.
3. If your study has not been completed submit a renewal to the IRB.
4. If you are no longer conducting the study or project submit a study closure.

You are required to keep copies of the informed consent forms and data for at least three years.

If you have any questions regarding the IRB decision, please contact Michael Gillespie, Research Compliance Officer. Mr. Gillespie can be reached by phone at (909) 537-7588, by fax at (909) 537-7028, or by email at mgillesp@csusb.edu. Please include your application approval number IRB-FY2022-187 in all correspondence.

Best of luck with your research.

Sincerely,

King-To Yeung

King-To Yeung, Ph.D., IRB Chair
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