

# A QUALITATIVE STUDY TO EXPLORE STAKEHOLDER'S VIEWS TO INFORM CULTURAL ADAPTATION OF A SELF-HELP CBTP MANUAL FOR PSYCHOSIS IN PAKISTAN

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## Abstract

A substantial evidence base supports Cognitive Behavior Therapy (CBT) delivered as Guided Self-help. National organizations in both the United Kingdom and the United States endorse it. CBT originated in the West, and there are suggestions that Western values influence it. Consequently, it is essential to adapt the guided selfhelp CBT manual to align with the specific cultural context of non-western clients to ensure its accessibility. The objective of this project was to develop guidelines for the cultural adaptation of a CBT for psychosis (CBTp) selfhelp manual for the local population in Pakistan, integrating insights from patients and their caregivers. Method: A series of qualitative studies were conducted with stakeholders, including patients and caregivers. The data was analyzed using thematic analysis. The investigation began with the identification of developing themes and categories. The themes that emerged from each interviewer's analysis of interviews were systematically compared and contrasted with those of other interviewers. Themes and concepts were triangulated to facilitate comparison and contrast of the data collected from the participating groups. Results: The findings from these studies underscored that patients and their caregivers in Pakistan adopt a bio-psycho-social-spiritual model to explain illness, emphasizing symptom elaboration for the client and strengthening their social networks. Conclusions: The findings from this study will be used to adapt a CBTP selfhelp manual for schizophrenia in Pakistan culturally. Once adopted, the manual will be evaluated for its clinical efficacy.

## INTRODUCTION

Schizophrenia spectrum disorders are a group of mental disorders that include thought, perception, emotional responsiveness, and social interaction disturbances (Hany et al., 2024). Many people who suffer from these disorders will experience hallucinations and sensations that occur without stimulus and delusions of beliefs that are fixed, false, and abiding (Arciniegas, 2015). The central illness of this category is schizophrenia, which has a typical onset in late adolescence or early adulthood and follows a course that splits into three phases: prodromal with a gradual diminution of positive functioning, acute with prominent psychotic symptoms, and a residual phase in which some

symptoms are present but less intense (National Institute of Mental Health, 2024). It is hypothesized to be the result of a complex interplay involving genetic vulnerabilities, neurochemical imbalances, particularly involving the dopamine and glutamate systems, and myriad environmental stressors, such as trauma, drug use, or significant life events (Figueiredo & Eduardo, 2024; McCutcheon et al., 2020; Singer & Yee, 2023). Diagnosis includes a comprehensive assessment based on DSM-5-TR criteria, which include a mix of positive symptoms- hallucinations and delusions- and negative symptoms- lack of motivation or social withdrawal (American Psychiatric Association, 2022). This

guided self-help manual on CBT targets schizophrenic spectrum disorders in a structured way to help individuals gain mastery over handling their symptoms through CBT strategies. More generally, this guided self-help manual bifurcates the CBT strategies into manageable sections that enable the use of independent and semi-independent strategies while working on alleviating distress associated with experiences of hallucination, delusion, and other related symptoms. The essential components include recognizing distorted thoughts, challenging and reframing harmful beliefs, and improving emotional regulation and problem-solving skills. Through a set of methodical exercises, individuals are encouraged to identify and gradually change patterns that contribute to their symptoms, promoting a more balanced way of perceiving reality.

Recent studies have supported the efficacy of CBT-guided manuals in the treatment of schizophrenia spectrum disorders (Kart et al., 2021; Naeem et al., 2014). Subjects who follow such guided manuals report declines in the severity of their symptoms, most especially in areas of paranoia, negative thoughts, and emotional withdrawal. It is a beneficial approach because it allows for flexible and self-paced involvement in the material, making it accessible and adherent. Thirdly, guided self-help manuals are often combined with time-organized sessions with mental health professionals to develop an economical but supportive treatment system. Self-help-guided CBT manuals have, in this sense, been thought to strengthen the patients' mastery and resilience required in the course of dealing with long-term psychotic expressions.

The self-help CBTp manual used as guided self-help is designed to be extremely simple and practical, assuming no experience of the person with mental health practices. It encourages, therefore, self-paced exploration of CBT strategies so that those who do not regularly get access to mental health services can reach them easily. These exercises, examples, and reflection prompts are designed to nudge individuals into enhanced self-awareness, resilience, and personal development, preparing them to face healthier and more fulfilling life challenges rather than psychotic challenges.

This paper reports a qualitative study that engaged stakeholders, including patients and their caregivers,

to explore their beliefs about illness and its treatment, particularly psychological treatments.

### Aims and Objectives

The primary aim of this study was to develop guidelines for informing the cultural adaptation of a CBTp-based self-help manual. Our objective was to explore the opinions and views of patients and their carers about psychotic illness.

### Method

#### Study Design

The study employed a qualitative ethnographic approach, incorporating personal interviews conducted via semi-structured formats with various participants, including caregivers and patients. The method of semi-structured interviews was provided an adaptable means of exploring the diverse perspectives of participants relative to their mental health experience, as well as what services are available to them in assessment of these treatment options. It ensures that the individual can anchor the self-help guide manual in critical themes and allows the respondents to have space to authoritatively say more in detail. In comparison to other standardized formats this kind of interview offers the respondent freedom to unfold their complicated thoughts and variety on experience.

For this study, semi structured interviews were conducted. Previously, Naeem et al. (2014) studied the cultural adaptation of CBT for psychosis in Pakistan with a psychiatrist well experienced in CBT and qualitative methods who undertook open ended interviews. In the present investigation, semi-structured interviews were used, as have been employed by the authors in previous investigations (Naeem et al. 2009, 2012, Naeem et al. 2009, 2010, Naeem et al. 2011). The investigators NN, and SD also analyzed the interview transcripts resulting from the earlier studies and the results of these studies, having collaborated earlier in the study. Our previous study explored themes and questions that are the focus of the present exercise. The questions we formulated ultimately established the groundwork for our semi-structured interview guide. The open-ended questions were refined with relevant prompts and cues aligned with the exploratory inquiries. The phrasing of questions was adjusted to improve the clarity of the interviews. The iterative process in the

study was maintained through insights gained from the interviewers and the research team.

### Study participants and their selection

Purposive sampling was implemented to recruit participants in this investigation.

#### Group 1: The patients

The investigation comprised interviews with ten patients who were diagnosed with schizophrenia, schizoaffective disorder, or delusional disorder according to the ICD-10 and RDC criteria. Participants were required to receive treatment at an

outpatient psychiatric clinic and have been afflicted with the disorder for a minimum of one year to qualify.

#### Group 2: Caregivers

Ten caregivers who agreed to participate in an outpatient psychiatric clinic were interviewed. Prior research has determined that caregivers accompany most patients. The findings indicated that caregivers have played a substantial role in decisions regarding treatment, healthcare system preferences, and follow-up care.

**Table 1: Characteristics of the participants**

Characteristics	Patients (10)	Caregivers (10)
Age (Mean)	years (range: 18–45)	40 years (range: 18–68)
Gender	Male: 9 (90%), Female: 1 (10%)	Male: 8 (80%) Female: 2 (20%)
Duration of Illness (Mean)	7 years (range: 1–30 years)	-
Education (Mean)	10 years (range: 0–16 years)	-
Diagnoses	Schizophrenia: 26 (78.8%), Schizoaffective Disorder: 7 (21.2%)	-
Urban/Rural	Urban: 20	Urban: 20

### Procedure

#### Collection of data and analyses

Caregivers and patients were interviewed in Urdu in rooms next to outpatient clinics. Each interview was recorded and varied between 30 to 45 minutes using the questionnaires. At the same time the interview process began, the transcription of the interviews began. We asked the participants for their telephone numbers on which they could be contacted if we needed some clarification on that question. All those involved were assured of their confidentiality and their anonymity. Only individuals on the research team had access to the data.

The researcher arranged the field notes about the non verbal communication and behaviours. As that interviewer began his interviews, he also began to analyze the interviews. With great care we selected a group of participants to share interview scripts with and invite them to learn from their perspective, confirm findings and better explain elements that emerged during the analysis process. As the

interviews took place within the scheduled interviews timeframe, interviewers received logistical support and guidance via Skype, telephone and video conferencing.

Using ethnographic methods outlined by Leyburn and Stern (2021), this study applied this study. The collection of this data also permitted examination of the respondents' perspectives within the cultural context in which they functioned (Jorgensen, 1989). The emergent design approach was employed in this study. Therefore, the respondents may be able to discern where further inquiry will be useful or take the results for confirmation (Creswell, 2014). Later participants were interviewed further to clarify these issues. Investigators followed up with participants to learn more about what was ambiguous from the data coding. This coding process established that the content and the questions referenced were examined thoroughly by Morse and Field (2013), as part of the coding process. According to Hammersley and Atkinson (1995), the examination required a need to for a thorough interaction with the data which was

achieved through multiple readings of the interview transcripts to determine the themes and categories that emerged from the data. Each participant was assigned a number to be able to track them throughout the process of transcription and reporting.

The interviews were analyzed to generate themes from the descriptive information contained in the database. When no further themes were revealed we had reached saturation. The themes were then condensed into codes and reorganized into broader categories: limited knowledge, peer influence on treatment and understandings of CBT and social

support. This paper presents the reported findings. The analysis included thoroughly examining the themes generated by each interviewer, highlighting both similarities and differences. A deeper examination of themes and concepts facilitated a comparison among various participant groups, enhancing reliability and accuracy. The validity was enhanced by providing participants with the transcripts, allowing them to verify that the content accurately represented their intended meanings.

The characteristics of the participants described below indicate the duration of their illness and their level of education.

**Table 2. Summary of themes explored through interviews**

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**Patients**

Perception of disease, its cause, and treatment preferences.

Awareness of its impact on daily life.

Presenting problems and chosen care pathways.

Engagement with modern vs. traditional treatment.

Their knowledge of psychotherapy/CBT

**Caregivers**

Views on disease causes and management.

Motivations for hospitalization and treatment expectations.

Awareness of medication adherence and social support.

Knowledge of psychotherapy/CBT.

It is magically transformed.

Religious devotion had intensified.

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**Analysis**

**Cause of illness**

Although the majority of patients indicated that psychotic symptoms were their primary concern, four patients expressed that mood-related symptoms were more troubling to them. The caregivers indicated that the primary reason for hospitalizing the patients was to manage the behavioral disorders. All patients reported that the illness had impacted their lives. One patient expressed, "I was unable to achieve my aspiration of becoming an officer because of this disease" (Patient 2). Factors contributing to health issues Most patients and caregivers associate the symptoms with psycho-social issues and stress. Approximately one-third of patients and caregivers believed that psycho-social factors were responsible.

One-third of the patients believed in a biological cause, while half of the caregivers shared a similar perspective. The majority identified multiple causes of the illness (refer to Table 3). As demonstrated by the following participant, my maternal cousin has the same illness, which is why I have it as well (Patient 1). This patient is experiencing familial issues related to anger, which have contributed to the development of this condition (Caregiver 3). Moreover, four caregivers reported additional causes, stating that it was due to their excessive religious activities. As one of the caregivers responded, "Yeh Namaz or Quran bht prhna lg gya tha is lia iska asar ho gya ha is pr" (caregiver, 4). Two of the caregivers reported that these symptoms are due to magic, as per reported "is pr toh jadu howa va ha" (caregiver, 9)

**Table 3**

<b>Patients' Views</b>	<b>Caregiver Views</b>
<b>Psycho-social causes</b>	<b>Psycho-social causes</b>
Stress(4)	Stress (4)
Domestic issues (2)	Interpersonal problems (2)
	Anger, impatience(2)
Excessive thinking(1)	
Personality (1)	Personality (2)
<b>Biological</b>	<b>Biological</b>
Genetics(1)	Genetics(2)
<b>Other causes</b>	
Do not know (2)	Accident (1)
	<b>Other Causes</b>
	Religious devotion (4)
	Spellbound (2)

### **Illness awareness and pathways to care**

The majority of the patients (8) reported experiencing a mental or psychological illness. At the same time, one believed that they had a neurological condition. Only one of them was aware that their condition was schizophrenia. Nearly all patients and caregivers reported benefiting from therapy, and they indicated that they would find help in the self-help manual if it were written in easy language (patients 1, 2, 3...). Additionally, some patients suggested enhancing the manual by including essential elements such as a proper routine for offering prayers, medication adherence, and psychoeducation about symptoms and diseases. The manual should encompass a chapter addressing life stressors and anxiety, as indicated by patient 4. Additionally, it should feature a section dedicated to medication adherence, as suggested by Caregiver 9. Furthermore, the manual must include a chapter outlining the symptoms and their management related to the disorder, as noted by caregivers 2 and 8.

### **Management of illness**

In Pakistan, the management of psychosis is approached through a biopsychosocial spiritual model by patients and their families. The medications are demonstrating positive effects for me, and I am convinced they are the only management of the diseases I am facing (Patient 1). If the patient complies with the prescribed medication regimen, the situation should remain

manageable; however, if adherence falters, external stressors could potentially exacerbate his condition, resulting in symptoms (caregiver 4). Approximately one-third of patients and their caregivers reported receiving continuous medical care. A caregiver suggested that their patient ought to receive psychological support. My understanding of therapy is somewhat limited; therapy may yield positive outcomes when appropriate guidance is offered (Patient 3). This will provide advantages for patients 5 and 6, as well as caregivers 1, 3, and 4.

### **Discussion**

The findings of this study underscore the necessity of adapting CBT for application in non-Western cultural contexts, aligning with previous research (Hays & Iwamasa, 2006); (Iwamasa et al., 2019; Naeem et al., 2010). Most of our research participants indicated that they believed their illness was a result of stress and either of their personalities. The data collected from this study have been utilized in a pilot culturally adapted guided self-help CBT manual for schizophrenia. A pilot study conducted in Pakistan demonstrated culturally adapted CBT psychosis efficacy, as noted by Habib et al. (2014). Furthermore, we revised the methodology previously utilized in Pakistan, where culturally adapted CBT has been tailored for psychosis, to evaluate the potential for adaptation with limited resources. The semi-structured interviews for this research were carried out with patients and their caregivers in the outpatient clinic. The current study also incorporates



interviews with caregivers. In this regard, we have revised our initial study design, as caregivers are an essential element of the decision-making process; understanding their beliefs and knowledge may serve as valuable tools in enhancing the therapy process. Our results closely mirror that from our earlier research in which investigator had adapted cognitive behavioural therapy for those with psychosis in Pakistan (Naeem et al., 2014). The results of our study also support previous research which has shown the relevance, accessibility and effectiveness of guided self-help CBT manuals for diverse populations, when such materials are culturally adapted. Work by Shea et al. (2012) with Mexican American women suffering from binge eating disorder has proven to the value of the use of such adaptation. Next the researchers adapted a CBT guided self help program to fit with participants' lived experience, including adding cultural values of familism, spirituality and cultural expression of distress. The same also prompted higher engagement and satisfaction levels which indicate that the guided self help CBT manual available is more effective when customized for the Pakistani population. For patients and families, they can help understand deeper the psychiatric condition and treatment. This study was influenced in its overall design and the use of stakeholder engagement, by the Southampton Adaptation Framework for CBT (SAF CBT) (Naeem et al., 2024) which suggests stakeholder engagement to inform the cultural adaptation of CBT. In doing so, their framework attends to the cultural idioms of distress as well as spiritual and family beliefs and to adapting core CBT elements in the ways that are consistent with effective and integrated therapy. These studies show adapting culture cannot be done wholly through application, but with it must be integrated with cultural beliefs, norms and therapeutic relationships for adaptation to be successful.

### Implications for Therapy and Research

The findings from this study were used to inform cultural adaptation of CBTp-based self-help, delivered as guided self-help. The study demonstrates that culturally sensitive methods must be fundamental for psychological treatment. Mental health professionals should incorporate local beliefs, language, and relevant cultural examples into their

guided self-help CBT manuals to enhance participation, comprehension, and compliance rates among psychosis patients and their families. Moreover, this research deduced that the adapted self-help guided manual should add the caregiver's involvement in the manual to strengthen family support for therapy, especially in Pakistan's collectivistic culture.

Moreover, our results suggest that the guided self-help CBT manual should be adapted to the cultural contexts based on extensive qualitative research. This paper highlights the need for adjustments to make the guided self-help CBT manual in Pakistan more suitable for use. Hence, the subjects studied in this article can be effectively used to enhance "culturally sensitive assessment and formulation." The results of this research agree with the comprehensive results that have already been discussed and thus suggest a culturally adapted application of CBT for depression, as well as for psychosis (Naeem, Ayub, et al., 2010; Naeem, Phiri, et al., 2010).

### Limitations

This study has limitations, notably that most patients and caregivers were from urban areas, which may affect its generalizability. Interviews have been subject to scrutiny regarding their validity.

### Conclusions and Future Directions

This was one of the steps done towards developing a culturally tailored CBTp based self help manual for Pakistan. In this paper we present a modification to the adaptation methodology outlined previously for CBT for psychosis in Pakistan. The results of this study were used to develop and pilot culturally adapted cognitive behavioral therapy for psychosis in a small randomized controlled trial. Future studies could expand the parameters of this study by including patients and caregivers throughout the spectrum of mental health issues and from all socio economic contexts. An extensive randomized controlled trial adaptation protocols must be validated. Because patients and caregivers in remote areas in which healthcare services are distant live with limited formal education, strategies must be developed to engage these patients.

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