

The Exploration of Stigma and Discrimination Among Patients Suffering from Depression: A Phenomenological Study

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Abstract

The current study aimed to investigate the lived experiences about Stigma and Discrimination among participants diagnosed with Depression. Transcendental phenomenology was used as a research inquiry by focusing on Husserl's concept of epoch and bracketing in order to get a fresh perspective towards the phenomenon under investigation. Purposive sampling was employed to recruit a sample of 10 participants diagnosed with Depression with a duration of at least one year from out-patient's settings of Lahore-based private and government hospitals. The DSM-V Cross Cutting Symptoms Measures level I were utilized to screen participants on comorbidity and the severity level of Depression. Furthermore, the interview was used as a data collection measure by exploring in depth semi-structured interview guide with the screened participants. The Van Kaam modified method for analysis was rigorously followed by the researchers through a series of steps such as epoche, phenomenological reduction (horizontalization and invariant constituents), and imaginative variation (individual structural and textural description). The composite description of the essence of the experiences revealed contextual factors of Stigma and Discrimination, experiences of stigma, and strategies needed to reduce Stigma and Discrimination about Depression. The study highlighted the need to develop culture-sensitive stigma reducing intervention to establish contact between patient diagnosed with Depression and the first level service provider.

Keywords: Phenomenology, Epoche, Phenomenological Reduction, Horizontalization, Invariant Constituents, Imaginative Variation

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1. INTRODUCTION

Depression is a crippling mood disorder with an estimated prevalence of 22% to 60% in Pakistan alone. Mascayano *et al.* (2016) and Pescosolido *et al.* (2013) found that the Stigma and Discrimination associated with Depression is the major determining factor behind the high prevalence of Depression that exists not only in Pakistan but also occurs across the world. According to Corker *et al.* (2016) around nine out of 10 people diagnosed with Depression report experiences of being stigmatized. Consequently, stigma itself has been described as a 'second illness' and speaking about mental health is considered as a social taboo. Stuart *et al.* (2012) found that Stigma and Discrimination have been experienced by patients with Depression in health care settings too. This happened by, for example, being provided with insufficient information to the patients, being regarded as lacking the capacity for responsible action, and being devaluated or discriminated. Taqui *et al.* (2007) claimed that due to the reasons stated above, a large number of people delayed treatment even after the years of onset or have been opting for spiritual healers and alternative medications that further complicated their illness.

In recent years, awareness of the issue has grown around the globe and it has hinted at the stigma being a clinical condition that remains poorly understood, examined, and treated. Although stigma associated with depression is less severe than other mental health conditions such as Schizophrenia, yet, high prevalence of depression makes addressing depression-related stigma an important public health concern. Choudhry *et al.* (2016) proposed that in Pakistan, factors such as low level of literacy and less awareness around mental health, limited financial conditions, and low levels of family support are contributing to huge gap in the treatment of depression. Therefore, stigma and discrimination related with depression needs to be explored in depth to address the considerable treatment gap.

With respect to previous literature, several qualitative studies such as those by Alvidrez *et al.* (2008), Mestdagh and Hansen (2014) and Mittal *et al.* (2012) have examined mental health stigma in detail. However, the majority of the studies conducted in Pakistan was of quantitative nature and analyzed gender differences (Khan *et al.*, 2015), estimating prevalence of depression and anxiety (Iqbal *et al.*, 2016) and explored clinical depression in Pakistan (Nisar *et al.*, 2019). Hence, there is a strong need to conduct a qualitative research to explore depression-related stigma and discrimination from the perspectives of the patients diagnosed with depression. Link *et al.* (2004) and Yang *et al.* (2007) asserted that such a research will help deepen the understanding of the lived experiences of stigma, and the processes through which stigma is developed,

flourished, and continued. Sunderji *et al.* (2018) argued that such an in-depth investigation would improve prevention and detection of Stigma and Discrimination, reduce chronicity, and improve social integration among patients diagnosed with Depression.

Keeping these considerations in mind, a qualitative research design was selected because it made the world of human experiences visible through direct interaction with the people in a flexible manner. Furthermore, qualitative research was preferred over quantitative research as the phenomena of interest had a special significance and personal relevance for the researcher, who being a mental health professional, found out that participants diagnosed with depression perceived their mental illness as a personal label during her clinical practice. Such experiences instigated a curiosity within the researcher to investigate the lived experiences and the meaning-making process of patients diagnosed with Depression. For this purpose, among the five traditions of inquiry, a Phenomenological framework of inquiry (Moustakas, 1994) was chosen as a research design to explore the phenomena under investigation. Moreover, transcendental phenomenology was preferred over other approaches within phenomenology with an intention to explore the structure of consciousness with the purpose of discovering the essential, invariant structure (or essence) of the phenomena of stigma and discrimination related with depression (Moustakas, 1994). This approach would help in inhibiting the researcher's own biases and assumptions to explore in greater details the essence of the participants' experience and to address these reflections in intervention that aims to reduce stigma and discrimination related with depression.

This study includes a brief explanation of stigma and discrimination related with depression and its relevant theories, followed by a description of transcendental phenomenology as qualitative inquiry, details of semi-structured interview guide, characteristics of the research participants, the data collection procedures, and the use of epoche and bracketing to gain an essence of the participants' experiences.

1.1. Stigma and Discrimination

Goffman (1963) describes stigma is a label or attribute that results in severe disapproval due to believed or actual individual characteristics, beliefs, or behaviours. According to Geiselhart (2010), the concept of stigma extended from the individual to the societal level i.e., discrimination. Furthermore, Pryor and Reeder (2011) formulated a conceptual model of Stigma and Discrimination by elaborating four interrelated components; public stigma,

self-stigma, stigma by associations, and structural stigma. Watson *et al.* (2007) explained self-stigma as the internalization of public stigma entailing fear of stigmatization. Whereas Alphen *et al.* (2012) elaborated that the public stigma is embedded in different beliefs of perceivers e.g., beliefs of responsibility for the onset of the disease, perceived severity, dangerousness, and control. Thirdly, stigma by association is expressed by Mak and Cheung (2008) as routinely devaluation from support group (e.g., family, friends and caregivers). On the other hand, Corrigan and Lam (2007) defined structural stigma as an indication of how societal norms and institutions, especially primary care staff, play a vital role in the initiation, development, and maintenance of stigma.

In addition, modified labelling theory suggests that due to prevailing societal attitudes, people diagnosed with Depression accept and apply negative perceptions and opinions to themselves. They internalized their stigma that may serve as a treatment-seeking barrier for people with Depression due to feelings of shame and embarrassment (Clement *et al.*, 2015). According to the 'stigma-induced identity threat model', people diagnosed with depression may react unintentionally (e.g., anxiety and apprehensions) or intentionally (e.g., escape and avoidance) to stigma, thus adhering to social avoidance and non-disclosure of mental health problems (Major and O'Brien, 2005). Therefore, the current study aims at examining experiences and views of participants diagnosed with depression to develop strategies to reduce stigma and discrimination related with depression.

1.2. Transcendental Phenomenology

Transcendental phenomenology was employed as a tradition of inquiry to explore the meaning-making process of the participants diagnosed with Depression. As Moustakas (1994) referred, searching for meaning of the experiences is the best source to acquire the essence of the phenomena. Thus, the process is transcendental as the phenomena was explored freshly.

To investigate the phenomena of Stigma and Discrimination about Depression, the phenomenological constituents such as lived experiences, intentionality, intuition, epoche, phenomenological reduction, imaginative variation, and essence of the experiences (Moustakas, 1994) of the transcendental phenomenology were explored. The lived experiences about Stigma and Discrimination associated with Depression were conceptualized as they were subjectively lived, from the perspective of participants diagnosed with Depression, with an aim to understand the reality of the experiences in the same manner as it was experienced by the participants. Moreover, the concept of transcendental phenomenology is strongly related to the intentionality which

is the consciousness of human experience. This intentionality, when sparked by intuition, provided an opportunity to understand the true nature of the phenomenon under investigation (Moustakas, 1994). According to Husserl (as cited in Yuksel and Yildirim, 2015) the comprehensive totality of the experience is gained through epoche by bracketing off all prejudgments to attain the essentiality of participants' lived experience. The epoche allowed the researcher to be objective and to describe the things in a bias-free manner to get to the heart of true essence of transcendental phenomenology.

Furthermore, philosophical assumptions such as ontology and epistemology were utilized to explore the "what and how" of the Stigma and Discrimination about Depression (Creswell, 2013). The ontology was employed by exploring the intrapsychic process of participants diagnosed with Depression (Moustakas, 1994). On the other hand, epistemology helped the researchers to focus on the construction of the reality (Robson, 2002). Following ontology and epistemology, social constructivism was utilized as a research paradigm to unfold the experiences of the participants diagnosed with Depression about Stigma and Discrimination associated with Depression, rooted in their societal and cultural background (Denzin and Lincoln, 2013). For that purpose, keeping in mind the theoretical framework, an open-ended, meaning and experience-based research question was formulated so that research participants could co-construct meanings about their experiences in a flexible and adaptive manner (Seidman, 2006; Moustakas, 1994; Creswell, 2013). It is as follows:

- What is the perception and experiences of the participants diagnosed with depression about stigma and discrimination related with depression?

2. DATA COLLECTION METHOD

To explore the participant's lived experiences about Depression related Stigma and Discrimination, in-depth interviews were considered an appropriate choice as potential participants might feel discomfort in narrating their stories. Therefore, an in-depth, semi-structured interview guide comprising five broad sub-questions were developed according to Kvale and Brinkmann's (2009) guidelines in Urdu language. The questions were aided with probes in terms of what and how, (Seidman, 2006; Guest *et al.*, 2006) around a set of predetermined open-ended sub-questions based on theoretical model of stigma and discrimination (Pryor & Reeder, 2011). Moreover, the current strategies and future ideas towards addressing depression related stigma and

discrimination were also included. Additionally, field notes were also utilized to document and present the researchers' personal reflections about data collection procedures (Creswell, 2013).

2.1. Sample and Sampling Strategy

Purposive sampling was employed to select the participants who were diagnosed with Depression so that they could reflect upon their essential meaningful experiences (Creswell, 2013). According to Moustakas (1994), in phenomenology, few individuals such as 1-10 who had lived experiences about phenomenon and who could provide comprehensive narrative of their experience, might suffice to uncover its core elements. Therefore, instead of focusing on breadth of the cases, initially 13 participants were approached who were diagnosed with Depression for at least one year and had been seeking treatment. Further, Cross Cutting Symptoms Measures Level-I (American Psychological Association, 2013) was utilized to screen for comorbidity and severity level of Depression as these conditions might impair the comprehension and understanding of the participants regarding the interview. A sample of three participants were excluded due to their comorbidity and higher severity level of the Depression. The excluded participants were thanked and debriefed about the reasons of not being included in the research (Seidman, 2006). The main study was conducted with a sample of 10 participants. Among the participants, 9 were females and 1 was male, educated up to 8th grade and were not experiencing an acute depressive episode.

Table 1. Demographic Characteristics of the Participants

| Sr. | Age | Gender | Education | Occupation | Income | Marital Status | Family System | Birth Order | Duration of Treatment |
|-----|-----|--------|-----------|------------|-----------|----------------|---------------|-------------|-----------------------|
| 1 | 24 | Female | B.A | Teacher | Rs.7000 | Unmarried | Nuclear | 2 | 3 years |
| 2 | 45 | Female | Matric | Housewife | Rs.1 lac | Married | Joint | 2 | 2 years |
| 3 | 28 | Female | Matric | Housewife | Rs.35,000 | Nuclear | Nuclear | 2 | 3 years |
| 4 | 35 | Female | Matric | Housewife | Rs.50,000 | Married | Nuclear | 2 | 8 years |
| 5 | 28 | Male | B.com | N/A | Rs.2 lac | Unmarried | Nuclear | 2 | 4 years |
| 6 | 25 | Female | Matric | N/A | Rs.50,000 | Unmarried | Nuclear | 10 | 3 years |
| 7 | 45 | Female | B.A | Housewife | Rs.1 lac | Married | Nuclear | 4 | 11 years |
| 8 | 20 | Female | B.A | N/A | Rs.50,000 | Unmarried | Joint | 2 | 5 years |
| 9 | 40 | Female | Matric | Housewife | Rs.20,000 | Divorced | Nuclear | 2 | 1 year |
| 10 | 40 | Female | Matric | Housewife | Rs.80,000 | Married | Nuclear | 3 | 3 years |

2.2. Procedure

A formal permission was sought for data collection from the medical superintendent and the head of the department of Psychiatry of Pakistan Medical and Dental Council (PMDC) recognized private and government hospitals in Lahore. The authorities were requested to refer those patients from outpatient units who were clinically diagnosed with major depressive disorder for the last one year and who were willing to be research participants. Initially, a pilot study was conducted on two participants diagnosed with Depression to assess the feasibility and comprehension level of in-depth semi-structured interview guide (Ismail *et al.*, 2018). According to Van Teijlingin and Hundley (2001), as contamination is of less importance in qualitative research, therefore researchers often use some or all of their pilot study data as part of the main study, therefore, the participants of the pilot study were not interviewed again and the data of pilot study was included in the main study.

Before conducting interviews with the participants diagnosed with depression, the researchers conducted an official meet up with each participant, to determine their willingness, and availability for the interview (Hurn and Tomalin, 2013). The written consent from was provided in native language to illustrate the purpose of the research, the participant's free-willed participation, assuring confidentiality, the rights of the participants to withdraw from research, the approximate time duration of the interview and the tape-recording procedures. The participants were assured that their recording would only be listened to by the researchers and the transcriber for research purpose only (Seidman, 2006). In addition, due to the sensitive nature of the research questions, participants were informed that they would be provided with free psychological services from a clinical psychologist after the interview to assure their psychological and emotional safety (Groenewald, 2004).

The interviews were conducted with each participant during their follow up visit in the outpatient unit of the department of psychiatry of the hospital according to their ease (Jacob & Furgerson, 2012). At first, bio data form was used to explore the social and cultural factors that shed light on each participant's demographic experiences (Mosutakas, 1994; Merraim, 2009). Additionally, the novice researchers facilitated in establishing rapport and trust building by presenting orally a comprehensive statement stating the goals of the study followed by an ice-breaker question to make the participants feel at ease in sharing their narratives. Once enough rapport and comfort had been developed with the participants, the sensitive and difficult questions were asked later (Ranney *et al.*, 2015). During conducting interviews, the researcher, being a clinical psychologist and a researcher, was aware that her lived experiences

might have an influence on her perception in comprehending the participant's experiences about Depression related stigma and discrimination. Therefore, to position herself in the research, the researcher bracketed her prior assumptions by extended her reading on the philosophical assumptions being employed in the current study such as ontology, epistemology, and other theories related to the depression, stigma and discrimination. The researchers developed a hypothetical picture about the phenomena under investigation and stated reflections explicitly. As the process of epoche started with the interview, Seidman (2006) proposed the use of active listening and field notes to maintain the integrity of epoche in transcendental phenomenology. Active listening was practiced by focusing on the participants' non-verbal gestures and the inner voices of the participants were explored by intriguing them about the meanings of their experiences with depression-related stigma and discrimination. Secondly, subsequent to each interview, field notes were prepared about the significant details of the interview procedure. The use of field notes along with audio recordings helped in acquiring deeper layers of the phenomenon (Lofland & Lofland, 1999).

Two interviews were conducted in a week with a duration of one and half hour to stay reflexive and attentive for the new exploration. The data collection was continued over six months until the phenomenon was exhausted or saturated (Seidman, 2006). The interviews were transcribed and coded with a number to ensure the confidentiality of the data (Groenwald, 2004).

3. DATA ANALYSIS

Moustakas's (1994) and Van Kaam's (1969) modifications for data analysis were selected for two reasons. Firstly, the researchers intend to explore each participant's textural (what) and structural (how) description of the experiences related with stigma and discrimination about depression. Secondly, the composite description of each participant's textural and structural description would help in gaining the essence of the experiences that can be incorporated into the culture-based stigma reduction intervention. The multiple steps of the Van Kaam's model for analysis were diligently followed throughout the data analysis procedure such as bracketing (epoche), phenomenological reduction, engaging in imaginative variation, and uncovering the essence of the experience.

3.1. Epoche

Moustakas (1994) stated that epoche is a requisite to capture the essence of the phenomena. The researcher practiced epoche by utilizing transcendental subjectivity, a state wherein the influence of the researcher is continuously examined to neutralize the impact of her presumptions on the phenomena under investigation (Neubauer *et al.*, 2019). This state was practiced by the researcher both in conducting interviews and analyzing data rigorously through reflective mediation. In reflective meditation, before reading the transcripts, the researcher recalled her own meaningful personal and professional clinical experiences with the patients diagnosed with Depression. She reflected on these experiences repeatedly and bracket off any application they might have to the current research by disconnecting herself from those memories. As the researchers moved toward receptiveness, they were able to concentrate fully, to listen to the audio tapes, and read the transcripts without colouring with their habits of thinking, feeling, and seeing (Moustakas, 1994).

3.2. Transcendental Phenomenological Reduction

Phenomenological reduction was carried out in series of steps such as horizontalization reduction of experiences into invariant constituents, clustering and thematizing the invariant constituents, and the final identification of the invariant constituents and themes by application. In the first step, transcripts were read thoroughly several times to develop an overall understanding and 205 statements were listed down, serving as a horizon that gives a distinct character to the phenomenon under consideration (Moustakas, 1994). No attempt was made to group statements or to order them in any manner.

In the next step, all horizons were clustered into invariant constituents by deleting overlapping and repetitive statements with an intention to discern meaning by reflecting on the verbatim transcript.

In the third level, invariant constituents and meaning units were thoroughly analyzed and sorted into core thematic label reflecting the experiences of the participants diagnosed with depression. Furthermore, core themes were verified through field notes, transcribed interviews, and the audio tapes for their clear expression and their compatibility in complete transcription. These core themes are elaborated as follows:

Table 2. Invariant Structures with their Corresponding Meaning Units

| Invariant Constituent | Meaning Units |
|---|---|
| Denial and avoidance to accept the diagnosis of depression | Fear of stigmatization |
| Fear of being mocked when disclosing the diagnosis of depression | |
| Perceived social myths as beliefs about dangerousness, controllability, weakness, madness | |
| Society accepts physical disease but not the psychological disorder | |
| Word of psychological illness indicates depression | |
| Lack of awareness about psychological disorder and its treatment | Lack of awareness |
| Lack of acceptance towards depression as a disorder | |
| Beliefs of magic, possession, as a reason of depression | |
| Depression will run in families | |
| Poor medicine adherence due to family pressure | |
| Depressive medication is sedative | |
| Nobody takes care of me | Need for support |
| Nobody loves me | |
| Kids are disconnected | |
| Husband is frustrated due to my depression and sedative effective of medicines | |
| Low frustration tolerance | |
| Non-congenial home environment | |
| Inadequateness of first order service provider in describing depression | Perception about professional service providers |
| Excessive emphasis on medicine adherence by primary care staff was perceived as a stigma | |
| Attitude of doctor perceived as cold and insensitive towards their sufferings | |
| Educational impairment | Impact of depression |
| Social isolation | |
| Loss of interest | |
| Physical impairments | |
| Society and family should have awareness about depression | Expectations |
| Professional care providers need to establish contact with us as a normal human being | |
| Need love and support to recover | |

Table 3. The Core Themes and their Corresponding Meaning Units and Invariant Constituents

| Core Themes | Meaning Units | Invariant Constituents |
|--|--------------------------------|--|
| Contextual Factors | Lack of mental health literacy | Misinterpretation of symptoms of depression as a physical illness |
| | | Lack of insight about treatment modalities for depression |
| | | Financial issues |
| Manifestation of Stigma | Detached attachment | Lack of acceptance towards depression |
| | | Inadequate information provided by the doctor |
| | Stigma experiences | Self-stigma, public stigma, anticipated stigma |
| | | Stigma practices |
| | | Myths of weakness |
| | | Myths of controllability |
| | | Myths of dangerousness |
| | | Myths of madness |
| Demography of stigma | | Gender-related norms |
| | | Role of participants in the family |
| | | Internalization of social myths |
| Strategies for Reducing Stigma and Discrimination about Depression | Individual level factors | Unconditional positive acceptance Role of family Regularity in follow up and adherence to medicines Providing psychoeducation |
| | Broader level factors | Establishing contact between patient and the first level service provider Team effort |

3.3. Contextual Factors of Stigma and Discrimination

The first theme is the contextual factors of Stigma and Discrimination about depression that unfolded important meaning units such as lack of mental health literacy. Mental health literacy refers to knowledge and beliefs about mental disorders that aided in their recognition, management, or prevention. All the participants primarily experienced physical symptoms such as muscle pain and headache. Sleep disturbance was also the most frequent problem among them. Due to lack of knowledge, these symptoms were misperceived as a sign of physical illness or the associated feature of the participant’s general medical condition such as diabetes and hypertension. It was also observed that cultural context played a vital role in understanding these deficiencies in knowledge. Since Pakistani culture is largely influenced by magical and superstitious

beliefs, therefore, superstitious reasons are easily accepted than medical or physiological explanations. As one participant reported:

“I fell ill... I was unable to sleep and I was so weak that I could not get up from bed.... I used to weep at my condition... then my family took me to a spiritual healer for exorcism. There they called a psychiatrist for the treatment so that I can recover soon.... But due to frequent exorcising.... due to the frequent usage of water of trinket.... The spiritual healer used to say that I am being possessed.... I used to weep due to tension that what happened to me... then I became suffocated...initially it was believed that someone has cast a spell over me”

According to most of the participants, they preferred to stay at their respective homes due to these beliefs. As the condition of the participants did not improve, they sought alternative healers as primary treatment modality due to the beliefs about somatic and organic factors before seeking trained and competent mental health professionals (both in public and private health services). In this scenario, traditional healers or local practitioners (such as *amil baba*), homeopathic and general physicians in Pakistan do not possess formal knowledge of mental health issues. Additionally, a lack of financial resources might have driven the participants' choice against consulting a psychiatrist or a mental health specialist and to visit general practitioners or traditional healers. Furthermore, seeking support from friends and family members proved a futile effort as in some cases, the family members and friends usually have limited knowledge about mental health problems. The family members usually considered these symptoms as normal reaction to stress.

“My husband told me that you were suffering from sleep problem and due to this problem, they got disturbed.... So, I used to tell him that you should consider that your wife is not well.... I was unable to sleep for days... I recite many prayers to improve sleep but I could not sleep. Even I asked my husband many times that I need medical help but they did not take it seriously”

Therefore, there was a significant time lag between the participant's first experiences of symptoms with depression and seeking professional psychological help. It was also observed that the psychiatrist proved to be the last resort for them and was only seen as acceptable when things were genuinely severe. Furthermore, a strong sense of ignorance and unacceptance was observed in professional service providers towards psychotherapy and the role of clinical psychologist.

3.4. Manifestations of Stigma

The contextual factors determined the manifestations of stigma in the participant's lives in the form of experiences of stigma associated with depression (self-stigma, public stigma, and stigma by association) practices of stigma (prejudices, discrimination, and stereotypes) and demography of stigma (gender norms, role of participants in the family). It was sensed that for participants with a mental health diagnosis proved to be particularly hard to deal with. They participants perceived the diagnosis as a label that reflects their flawed personalities. As one participant shared:

“When doctor told me about depression then I just thought that it should not have happened. Depression is due to tension. Overthinking caused depression. I feel so bad after diagnosis”.

Furthermore, their emotional shock got intense when the participants received inadequate information about the depression from the professionals. Some of the participants were briefed about biochemical abnormalities as a cause of depression while others were informed about negative thinking as a trigger to initiate depression. For the participants, professionals were the source of comfort and emotional catharsis for them but due to inadequate information provided by the professionals, participants felt that the professionals maintained an emotional distance due to stigma associated with depression. Other than the professionals, family is the first source to seek help from, but due to perceived detachment of the professionals, the participants assumed that the family might stigmatize them with negative reactions due to the diagnosis of depression. Their initial perception was reinforced when the participants disclosed their diagnosis and the family members stigmatized and labeled them as a “mental patient” or “mad”. Such words or phrases indicated that family played a crucial role in initiating and maintaining stigma. It was observed that the family portrayed the existence of patients with depression in their home with a label that stimulated three important components of stigma such as stereotypes (myths of weakness, controllability, dangerousness, and personal responsibility), prejudice, and discrimination in the participants’ lives. One participant shared these myths as:

“My father did not understand my depression, and he thinks that I can control my depression but I can’t control my depression... people in our society are not kind to anyone. They just make you an outsider... make you an outcast...if you are different”.

It was observed that these experiences compelled them to internalized their pain of depression deep in themselves, made them detached and alone along with their difficult emotional experiences. The participants’ narratives

indicated that being a depressive patient they were living in the shadow of fear, helplessness, and isolation as they experienced dejection and dissociation from people of significance in their lives. They shared their experiences as:

“Depression became a part of my life. I have been living with it and I have been living with this other life. My family think that I am normal who’s not into studies. They really don’t know what is happening with me. I have associated my life with depression”.

Further along with internalization of stigma, the participants’ experiences led them to believe that the family members and the professional staff will underestimate the extent of difficulties associated with depression. Therefore, they intentionally decided to keep their diagnosis as a secret as they believed that their act will preserve the family worth against potential stigma. It was observed that this decision was also influenced by the demography of stigma such as gender and the role of the participants within the family. The five participants’ decision to hide the diagnosis was made in order to live with the in-laws with dignity and self-respect. In addition, two participants who were mothers of daughters, hid their depression under the complain of headache as they believed that their depression will create a hurdle in their daughters’ marriage proposals. As one participant shared their fear:

“Mental illness is a scary word. People used this word that you are mad and got to hospital. So why should I have used this word for me. I used to hide depression as headache. Everyone knows only about my headache in the family and they asked me to get the treatment. My mother-in-law also knows about my headache. But nobody knows about my depression. I did not disclose it in me in laws as people had misconception that it would run in family and my daughter will face issue in their marriage”.

Moreover, the participants articulated their concerns that their family members consider medical treatment for depression unnecessary; rather they stigmatize the psychiatrist and treatment-seeking behaviours. It was reported that the family members have these perceptions deeply rooted in the prevailing norms of the society about depression. The participants shared their feelings as:

“There is stigma with depression. You know it’s like something that you don’t want to talk about. It is not just in our society but everywhere it is same...especially in our society, it is like a taboo that you don’t like to talk about. You don’t talk about psychiatric help. Like me... many people in our society have depression because there is an alarming situation in our society but we are not allowed to talk about it. We worry about what other people will

think and this is the problem. We are just focus on people, in our society, our neighbours and on everything that we forget ourselves and this is the problem”.

The combination of all contextual factors and manifestations of stigma elicits the reasons of stigma and discrimination about depression rooted in the social and cultural context of the participants.

3.5. Strategies to Reduce Stigma and Discrimination About Depression

This theme indicated the strategies highlighted through participants' narratives to reduce Stigma and Discrimination in terms of depression. These strategies can be divided into factors required at the individual level and the broader level. At the individual level, unconditional acceptance, role of family, regularity in follow-ups, and medicine intake were considered as important prerequisites. It was observed that the participants were struggling to redefine the self in connection with others. They were voicing their need for acceptance from the significant members of their lives, reflecting their craving to have a sense of affiliation with other family members. A strong need to listen to the participant non-judgmentally and unconditionally was evident across the interviews. The participants' narratives revealed that they also wanted their families to value them as individuals who need love, respect, and dignity. It was observed that participants who have supportive families recovered sooner as compared to those who have rejecting families. Therefore, the role of family seemed to be of utmost importance in facilitating support and generating positive outcomes. Furthermore, medicine adherence was considered to be an important component in empowering personal strength in reducing Stigma and Discrimination about depression. It was observed that participants who have strong medicine adherence improved considerably.

“I also have non-congenial relationship with my mother...but now they are improving as I am taking psychiatric drugs. My irritated mood improved a lot. I was fed up with my home environment. Now my frustration tolerance improved a lot due to medicines. Otherwise, I was very short tempered. Now my relationship is improving day by day”.

At the broader level, it was observed that for participants diagnosed with depression, their family members carry stigma and discrimination about depression due to lack of mental health literacy. The participants assumed that as the providers of care, primary care staff has the knowledge and experience that patients and their families do not possess. The only way to bridge the treatment gap created through stigma and discrimination is to share the information in a comprehensible and structured way i.e., psychoeducation. Furthermore, participants also need contact with the professional staff. The

participants assumed that the psychiatrists had detached attachment, lacked understanding, and emphasized more on medicine adherence. A major difficulty in overcoming stigma, and indeed probably one of the causes, is that it is very hard, perhaps impossible, for those who have not experienced depression to understand what the individual with depression is experiencing. As one participant shared:

“Doctors need to loosen up a little. Like...don’t be so direct that why I am not taking medicines. I know that if I am not taking medicines, it is bad for me. They need to understand that it is hard. I did not choose my depression. I want to try to make them understand this but I don’t have the will.... I just don’t want to sleep all day. That’s why I did not take them. It’s not like that I don’t want to get better but it is hard for me. I wished that they had understand me...my life”.

Lastly, a strong team effort and a collaborative role is required as prerequisites in the recovery process. A strong sense of ignorance and unacceptance was observed in professional service providers towards psychotherapy. However, two of the participants who were referred of the psychotherapeutic intervention by the psychiatrists and taking sessions regular felt the improvement in their condition. According to them, along with regular follow up and medicine adherence, a collaborative role is required as a prerequisite in the recovery process. They stressed the importance of team work in reducing stigma and discrimination related with depression.

3.6. Imaginative Variation

In this step, experiences were clustered in the form of textural and structural description as follows:

Individual Textural Description. These narratives were based on “what” of the experiences of each participant revealing a sense of separation and disconnection due to blaming attitude of the family. The participants perceived themselves as weak and internalized their pain of unattended concerns as self-stigma but deep inside they longed to be treated empathetically and without discrimination. They wished that their family and primary care providers acknowledge their resilience in the face of adversity and give them support to get through their current difficulties with depression.

Individual Structural Description. The individual structural description revealed the 'how' of the participant experiences. A lack of awareness about psychological disorders and their treatment was evident across all the interviews. Manifestation of the symptoms of depression were considered

drama, possession, and the impact of black magic. A cry for help was snubbed, rejecting the notion of medical cure and emphasizing self-management. Furthermore, consultation with general practitioners worsened the symptoms of the depressive disorder and professional detachment of the psychiatrist was perceived as ruthless, lowering the self-esteem of depressive patients. These experiences illustrated the reasons of a dire need to be unconditionally accepted among the participant's narratives.

Essence of the Experience. The essence of the experience indicated that contextual factors, such as lack of mental health literacy, seemed to be the core reason behind the stigma and discrimination associated with depression, and contributed a significant time lag in seeking professional psychological help at the appropriate time. Therefore, initially, the participants preferred traditional healers and general practitioners as a treatment choice for depression. Later, as their condition worsened, they were referred to psychiatrists, where they were finally diagnosed as a patient with depression. The participant's, narratives indicated that inadequate information provided by the psychiatrist seemed to increase their catastrophic thinking about depression. These worries seemed to stem due to the prevailing cultural myths associated with depression, such as myths of weakness and personal responsibility. Therefore, a strong feeling of disapproval toward depression was observed as it was perceived as a symbol that reduced the worth of a person. Due to these perceptions, it was evident throughout the narratives that participants initially keep their diagnosis secret but in the pursuit of emotional support from family members, they disclosed their diagnosis but received negative reactions and discriminatory behaviour from them. As a result, depression was experienced as a social taboo and participants internalized their experiences in the form of guilt, shame, and hopelessness. It was observed that along with these experiences, the gender and the role of the participants in the family also seemed to be compelling in their efforts to avoid disclosing the diagnosis of depression. However, it was sensed that the supportive family members proved as a prognostic factor in regular follow ups and strong medicine adherence.

The essence of the experiences of the participants diagnosed with depression highlighted the need to foster individual and broader level factors. At the individual level, a dire need to disregard the diagnosis of depression as a personal identity of the participants was observed by providing unconditional acceptance, love, and support. Continued family support, strong medicine adherence, and regularity in follow-up also seemed to improve the participants' condition. On a broader level, providing psychoeducation to decatastrophize the participants' thoughts and to deal with family biased perceptions about

depression were perceived as having significant importance. Secondly, for primary care staff, awareness in providing contact with the participants diagnosed with depression was required in making consultancy meaningful to reduce stigma and discrimination about depression. Lastly, collaborative work of patients, family members, psychiatrists, and clinical psychologists was perceived as a necessary prerequisite for reducing stigma and discrimination about depression.

4. DISCUSSION

This study aimed to investigate the experiences of stigma and discrimination related with depression among participants diagnosed with depression. The analysis of the data revealed that the essence of the phenomenon consisted of contextual factors of stigma, manifestations of stigma, and the strategies needed to reduce stigma and discrimination about depression.

The essence of the participants revealed that the contextual factors such as lack of mental health literacy seemed to be an important feature of stigma associated with depression and it was deeply embedded in the social, financial, and cultural contexts of the participants. Consequently, a significant treatment delay was observed in all the participants' accounts, making this finding in line with McGorry *et al.* (2011) who found that the delay in treatment occurred due to many reasons. Such reasons include belief in black magic, fear of possession, and a view to seek help only when the condition of the sufferer was exceedingly bad. Furthermore, as culture and religion played significant roles, spiritual healers and general physicians were the first options to reach out to for spiritual and medical help before seeking help from an officially trained and professional mental health expert. Furthermore, Khan *et al.* (2011) affirmed that full consensus was achieved on lack of awareness and education as the main cause of the stigma.

The essence of the participants' narratives indicated that the psychiatrist's biological explanation of the disorder and the emphasis on medicine adherence was experienced by the participants as a detached and discriminatory attitude. Minas *et al.* (2011) reported similar findings about the prevailing stigmatizing attitudes amongst health care workers towards patients with depression. A number of researches on stigmatizing attitudes, including those by Newton-Howes, *et al.* (2008); Schulze (2007) and on stigmatizing behaviours of health care professionals towards people with mental health problems by Burke *et al.* (2016) and Thornicroft *et al.* (2009), indicated that the attitude of the primary care staff might be influenced by prevailing mental

health stigma and the need to maintain a level of professionalism with the patient. This could be the reason behind the health care providers' professional coldness.

In the current study, it was observed that stigma and discrimination about depression manifested itself through self-stigma, public stigma, and the stigma by association. Lasalvia *et al.* (2013); and Thornicroft *et al.* (2009) have all demonstrated similar patterns and reported experiencing discrimination in a sample of depression patients. Additionally, these results are in line with the findings of the study by Pryor and Reeder (2011) theoretical model of Stigma and Discrimination and Weitkamp *et al.* (2016) research findings. According to Hanafiah and Van Bortal (2015), it seemed that the components of stigma are working in collaboration with each other and highly influenced by the social and cultural contexts of the participants. This might be the reason that some participants in the current study employed social avoidance and non-disclosure to cope with internalized stigma, findings that are supported by the literature, such as the studies by Burke and Kraut (2016); and Vass *et al.* (2017). Also, the demography of stigma also played a vital role in maintaining stigma about depression. These expressions are widely recognized in research literature such as in the studies of Clement *et al.* (2015); and Corrigan *et al.* (2016).

Lastly, the essence of the investigated phenomenon highlighted different individual and societal level factors needed to deal with stigma and discrimination about depression. The findings indicated the participants' need for unconditional love and acceptance, supportive family, and a strong medicine adherence. At a broader level, the findings also highlighted the need to foster prognostic factors, such as, collaborative role of psychiatrists, clinical psychologists, and the family members in dealing with stigma and discrimination about depression. Furthermore, it was evident that a psychoeducation and a contact approach is needed to address stigma and discrimination about depression from the primary care staff and the family members. These findings are in line with Huggett *et al.*'s (2018) study indicating the need for developing or adapting and implementing culture-based stigma reduction intervention for depression.

4.1. Strengths

To the best of the researchers' knowledge, this is the first qualitative study incorporating transcendental phenomenology as a method of inquiry to explore stigma and discrimination among participants with depression in Pakistan. An in-depth semi-structured interview guide was developed and used that helped understand the quality and content of the essence of the participants'

experiences. Additionally, formal and validated screening procedure such as Cross Cutting Symptoms Measures Level-I (American Psychological Association, 2013) was employed to rule out any comorbidity with depression to investigate stigma and discrimination associated with the life processes of the participants with depression.

The essence of the experiences of the participants with depression provided an indigenous perspective embedded in the culture contexts of the participants, highlighting the strategies needed for stigma reduction intervention. At the contextual level, this study elicited factors such as lack of mental health literacy at the family and societal levels about depression. The only way to bridge the treatment gap created through stigma and discrimination is to share the information in a comprehensible and structured way i.e., psychoeducation with the family and the participants diagnosed with depression. The role of the family proved as of cardinal importance in the recovery process or worsening the symptoms. In addition, to improve the professional detachment of the professionals, the need for contact intervention emerged with an aim to overcome this interpersonal divide and to facilitate positive interaction and connection between the participants diagnosed with depression and the first level service providers of primary care staff. Also, a need for collaborative role among the psychiatrist, the participants, the family and the clinical psychologist was observed to deal with stigma and discrimination about depression as they would create a sense of empowerment and boost self-esteem of the participants.

4.2. Limitations

This study has a number of limitations. First, the sample consisted of the participants diagnosed with depression who were willing to disclose their experiences and were seeking medical help and treatment. The accounts of the participants not seeking professional help and managing depression at home on their own may add important reflections. Second, it could be argued that there was only one male participant given that depression is a condition commonly associated with females. The researchers acknowledged that they missed the chance to add male participants to explore differences and similarities across and within the cases in detail due to time limitations.

4.3. Implications

The essence of the experiences indicated the pressing need of improvement of mental health services especially in relation to need-based policies, practices, and proper implementation and evaluation. In addition, an

awareness-based stigma reduction intervention needs to be provided to primary care staff and significant support providers for training them in psychoeducation and normalization about depression to reduce the treatment gap in mental disorders. This awareness would help become more thoughtful with regard to their responses, i.e., stigmatizing attitudes and showing thoughtfulness about discriminatory behaviours.

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