

A qualitative study on living a meaningful life with chronic mental health conditions

Sushma Kumari

Assistant Professor Social Work, Human Behaviour Department, Institute of Human Behaviour & Allied Sciences (IHBAS), Delhi, India

ABSTRACT

Background: Mental health conditions are generally seen as involving lifelong adversities with high vulnerability to social marginalization, health hazards, and economic deprivation. In spite of these adversities, many individuals struggling with mental health conditions are leading outstanding lives of courage and dignity. They contribute equally to society, just as other members who do not have mental health conditions. Existing scientific research has largely focused on the negative outcomes associated with mental health conditions, often overlooking those who are living meaningful lives. Considering this, the present study aimed to shed light on the lived experiences of personal recovery among individuals with chronic mental health conditions that enabled them to lead meaningful lives. **Methodology:** The present study employed an exploratory qualitative research design. Individuals with mental illness who were stable on treatment and capable of recognizing their functional, occupational, and social abilities for leading meaningful lives were included. All participants were assessed in detail through in-depth interviews about their lives and personal journeys after obtaining their consent. **Results:** The main themes that emerged from the study were related to personal aspirations for a better future, recovery needs, retention of gainful employment, and being acknowledged as a respected person rather than merely a patient. **Conclusion:** This study could help change the prevailing attitudes among the general public regarding individuals with mental illness by demonstrating how they can challenge the deficits associated with mental illness and excel in the specific areas they engage in.

Keywords: Chronic mental health condition, meaningful life, personal recovery

INTRODUCTION

Generally, mental health service users often experience that they are not heard and portrayed positively. The much-needed help is also being denied at some time. Furthermore, even after a substantial level of recovery from mental health conditions, the identity of a persons with mental illness rather than a person remains the same. It can be detrimental to their wellbeing and recovery. The identity of a 'mental patient' also leads to diminished social networks, a loss of social roles, limited contact with friends and family, and increased contact with health professionals and fellow service users.^[1] The societal concepts shaped by media and old movies that persons with mental health conditions are a threat to society are still prevalent among common people. It spreads a widespread stigma, the effects of which are not


just limited to discrimination and non-acceptance but may lead to abuse as well.^[2] The stigma and nonrecognition associated with it, further lead to delayed treatment and subsequently poor recovery and quality of life.

Many individuals develop resilience even after being diagnosed with mental illnesses including schizophrenia,^[3] depression,^[4] and PTSD.^[5] They can lead a productive and meaningful life even while having symptoms^[6] and are contributing equally to society as others who do not have any mental illness. Moreover, the significant changes within the Mental Health Care paradigm consider Mental Health Service Users (MHSUs) equal partners. In India, the MHSUs started joining the central/state Mental Health Authority/boards of provider agencies/partners in mental health care or developed

Address for Correspondence:

Dr. Sushma Kumari, Assistant Professor Social Work Human Behaviour Department, Institute of Human Behaviour & Allied Sciences (IHBAS), Delhi, India
Email: sushma-ihbas@delhi.gov.in

How to Cite the Article: Kumari S, A qualitative study on living a meaningful life with chronic mental health conditions. Indian J Psychiatr Soc Work 2024;15(2):11-6.

| Access the Article Online | |
|--|---|
| DOI: 10.29120/IJPSW.2024.v15.i2.633 | Quick Response Code  |
| Website: http://pswjournal.org/index.php/ijpsw | |



resources in the form of peer support.^[7] However, there is a general tendency even among mental health professionals to give more focus on the deficit one has rather than the strength one possesses. The practice of acknowledging only clinical recovery from symptoms of mental illness imposes a heavy burden on the individual's overall well-being. A full recovery is difficult to obtain within this clinical understanding and many have found it hard to create a meaningful life.^[6] So, there is a need to shift the foci from the deficit-based approach to a more strength-based approach that increases the overall well-being of persons with mental illness.^[8]

Understanding recovery from the persons with mental illness perspective indicates the process of adaptation and development through which the individual overcomes the negative personal and social consequences of mental disorders. This adaptation helps for a self-determined and meaningful life. It does not necessarily indicate the return to life before becoming ill or full functionality, but rather the growth beyond the premorbid sense of self.^[9] This recovery growth is measured as accepting mental illness, finding hope for the future, re-establishing a positive identity, developing meaning in life, taking control of one's life through individual responsibility, spirituality, empowerment, overcoming stigma, and having supporting relationships.^[10] More importantly, when the MHSUs have a defining voice in shaping the system to meet their needs, their input needs to be solicited, especially on those conditions where the role change would influence the understanding and orientation for the future development of mental health care. There are only a few investigations that aim to understand recovery from mental illness through personal narratives or subjective perspectives as compared to applying objective methodologies.^[11] Recovery from mental illness involves a personal process that evolves throughout one's adaptation to the illness and occurs in stages with increasing self-awareness and decreasing dependence on external supports, as personal and social capital is rebuilt. Therefore, it includes both the objective indications of a reduction in symptoms, as well as the development of new meaning and purpose in one's life that helps to deal with the effects of mental illness.^[12] The existing scientific research mostly focused on the

negative outcomes associated with mental health conditions and ignored those persons who are living a meaningful life. Therefore, understanding recovery from a person's perspective that involves the development of new meaning and purpose in one's life would help to deal with the effects of mental illness in a better way. Considering the above, the present study was an attempt to elucidate upon the lived experiences of personal recovery of persons with chronic mental health conditions that helped them to lead a meaningful life.

Aim

The present study aimed to explore how individuals diagnosed with chronic mental health conditions overcome and adapt to these conditions through their subjective experiences.

METHODOLOGY

Study design: The study used an exploratory qualitative descriptive phenomenological design guided by the work of Benner and van Manen.^[13,14] The steps involved were (a) selection of the phenomenon of current interest (b) exploring the experience of persons with chronic mental health conditions (PWCMI) as meaningfully lived by them rather than as observed by others, (c) reflection of the main themes that characterise the experience and structure the phenomenon of leading a meaningful life and challenges faced (d) described the phenomenon through the use of participants' voices.

Study Participants: Ten PWCMIIs visiting regularly the Out-Patient Department for follow-up treatment at the Institute of Human Behaviour and Allied Sciences (IHBAS), Delhi were included in the study after getting their informed consent. All the participants maintained well on treatment from the last 2 to 6 years and were aware of their functional, occupational, and social abilities for leading a meaningful life. Eight of them were staying along with their families and getting emotional and financial support from them. One person with mental illness was independently living in a working women's hostel and another one lived in the shelter home and was taking responsibility for her well-being. The age of the participants was between 25 to 55 years and were mostly females. Seven had Schizophrenia and three had Schizoaffective or Bipolar Affective Disorder. Out of Ten participants,

four were married, three were divorced, and three were unmarried. Most of them were belongings from middle to lower socio-economic class. Three of them had regular employment in the Government/ corporate sector as per their qualification. Five had part-time paid work but were working less than their qualification and getting very little remuneration.

Participants were explained their rights to leave the study at any time. The information shared by them was kept confidential and anonymous. The ethical considerations were taken care of.

Data collection and analysis: The participants were interviewed individually on six to seven separate occasions for 30 to 90 minutes. The analysis of preliminary interviews was used to generate issues for clarification and further questions in follow-up interviews.

The data analysis focused on thematically revealing and interpreting the meanings of the lived experience from the participants' perspective using a phenomenological method described by Van Manen. ^[15,16] The following procedures were followed:

1. All interviews were noted down, and each text was read numerous times to gain a sense of their whole experience of living a meaningful with severe and chronic mental illness.
2. Significant statements, directly related to the phenomenon of leaving a meaningful life were identified. These were read and re-read to articulate conceptual meanings and explore essential qualities of described experiences. Emerging conceptual themes were discussed individually with the participants to seek a consensual validation of the conceptual meanings.
3. Components of each participant's statements pertinent to each meaning unit or theme were highlighted. The suitable statements were clustered and finally consolidated into a comprehensive account.

RESULTS AND DISCUSSION

The main positive outcome themes from the present study were aspirations for a better future, getting and retaining good jobs, hope, positive outlooks toward recovery, and an adequate support system. The positive outcomes show the positive adaptation across a

range of circumstances. Self-stigma was the major blockade that interfered with their daily life.

Theme 1 and 2: Aspirations for the future and getting and retaining good jobs

It was about having a strategy /concrete plan for the future and hope that the future would be better and more peaceful. The participants had mixed reactions about their future ranging from uncertainty (fear) to having a concrete strategy for the future. Despite all adversities, most of them were hopeful for a better future. One of the female participants, was a government teacher, initially, she was on the verge of losing her job. During the symptomatic phase of her illness, she did not report to her office, the reasons for her unauthorized absence from her job for almost five years, expressed:

“Initially, when my illness started and got a psychiatric diagnosis along with multiple hospital admissions, my family and I tried to hide the sickness due to the fear that no one wanted to interact with us and get married to my sisters. However, I had a hope that things would change in the future after getting proper treatment and guidance from IHBAS.

Further, she expressed that you know, I started searching for another job, however, the psychosocial counselling services encouraged me to approach my competent authority to present my situation, and ultimately, I am permitted to report to and continue my job. Now, I am working.

The experience concerning the need for recovery from one's illness evolves throughout one's adaptation to the illness situation. It occurs in stages with increasing self-awareness and decreasing dependence on external supports. ^[12] Another female participant, a law student has been undergoing treatment for schizophrenia for the last eight years at IHBAS. She developed mental illness after one year of her marriage. Her husband abandoned her following her diagnosis and sent a notice for divorce. She fought her court case and also started working on a part-time basis under a senior advocate, expressed that:

“During my illness phase, I was not in a position to think about myself.... forget about the marriage and the future. I loved my husband a lot. He made me feel isolated and mentally dependent on others; I know ... lacked the skills

to regulate my emotions, start calling the person whom I loved very much, and sometimes--- get negative comments from them ---, I found difficulty in managing everything alone. They harassed me mentally and physically. But I don't know how I could be able to change myself.... It could be the help and support I received from various agencies... IHBAS, Delhi State Legal Services Authority, or Delhi Commission for Women where my feelings and needs were validated."

Regarding her plans and hopes for the future, said that

"I am already getting trained for court proceedings under the guidance of a senior High Court advocate....and hopeful to be involved on a full-time basis after getting sufficient experience and a bachelor's degree. You know... I fought my divorce case and got my maintenance from my Husband."

It was encouraging to note that regardless of the problems, participants mostly had a positive outlook. More importantly, there were negligible reports of absolute hopelessness among them.

The participants had concrete plans and hopes for a better future. It reflected their intentions for survival, overcoming the challenges of mental illness, and living a productive life. Some of them also experienced fear and doubts regarding their future in the initial phase of their illness and gradually developed resilience to it. The narratives show that addressing psychosocial issues paves the way for participation in society, even when suffering from mental health challenges. These findings are consistent with the results of previous research. ^[2,16,17] It shows that Coping with symptoms constitutes a key feature, but recovery is regarded as more than that as it includes social and occupational functioning, too.

Theme 3: Available family support system

Adequate support to overcome serious mental illnesses and understand from a personal development and lifeworld perspective is crucial for empathetically looking at the PWMHI conditions instead of viewing them as chronic cases of the disease. ^[18] On many occasions, regardless of the family cohesiveness and shared responsibilities among family members for caring for their mentally ill

relatives, their relationships were affected. Frequent unresolved conflicts were present among them. Contact with other relatives and neighbours remained very minimal. Despite all, eight of them were residing with their families. One of the participants beautifully narrated it as:

"I did everything to maintain my family life but initially my husband and children did not understand my condition and always blamed me for working at a slow pace. I needed time to look after myself, my family, and my professional life. My husband suggested I to take voluntary retirement from my job to maintain equilibrium. I took voluntary retirement. However, my husband encouraged me to focus on my health and wellbeing. I learned cycling and Yoga. Currently, helping other neighbours to do yoga regularly. I regain my lost self-image, too."

The theme of experience of available family support not only included the relation between the caregiver and the cared for, but it also involved their individual and common relation with the world. The present experience of a PWMHI reflects that even the empathetic understanding of their feelings and emotions would have a long impact on bringing a change for leading a meaningful life. It helps them in developing adaptations and resilience to chronic mental health conditions. The present finding supports the study of Ashwin and Deb (2020)^[2]

Theme 4: The Experience of stigma and prevalent Prejudice

The attached stigma and prejudices to mental illness in society contribute to a sense that PWMHI experiences do not matter to others. Others are not willing to understand them and acknowledge the suffering of a mentally ill person. The prevailing negative public attitudes affect the lives of the severely mentally ill and their families. Even with a small mistake, people start having doubts about their capability. PWMHI also develops a feeling of self-stigma and doubts about their self-capabilities. They generally begin focusing on their self-limitations. A recovered persons with schizophrenia who had a history of relapsing symptoms on several occasions. She was a business entrepreneur, with a diploma in event management and was staying in a paying Women's hostel narrated her experience as

“I am staying and managing everything alone, the symptoms of mental illness gave me a level, and from that I am unable to get rid of it. Once, I settle one issue, some or other problem arises. Initially, I wouldn't be able to work outside as fearing about my suspicious behaviour and thought that when people would know about my illness. They would remove me from the job. So, I started avoiding getting help from others thinking that they considered me a poor fellow or mentally ill.” Now do not have any option whether to hide or reveal it have to take medicines regularly and earn for survival.”

Most of them felt a need to make the world more accepting, more tolerant, and less threatening for them. The PWMHIs started finding faults in their self-behaviour and skills and focused on their limitations. Their experience of attached stigma and prejudice is seen as the hiding of talking openly about their illness and fearing being excluded from all activities that require social interaction. They try to deal with the situation by withdrawing from it. This leads to their social isolation and further exclusion from society at various levels.

CONCLUSION

Living a meaningful life means recovering a life with participation in all facets of civic and economic life as an equal citizen. Looking at and understanding a situation through the eyes of PWMHI is unique and different from others. The present study highlighted the need to adopt a Psychosocial and humanistic focus that enables PWMHI's recovery, leading to a meaningful life. This is a need that the healthcare system and society to be more inclusive of them by involving them as partners with shared decision-making on their treatment and rehabilitation plans.

Acknowledgment: The author thanks all study participants for their cooperation and time.

Financial Support: The author did not receive any financial support to conduct or to publish this research.

Conflicting Interest: The Author declared no potential conflict of interest for the research, authorship, and/or publication of this article.

Prior presentation: A part of the paper was presented during the 75th Annual National Conference of Indian Psychiatric Society (ANCIPS), at Le Meridien, Kochi, Kerala, India from 18 - 21 January 2024.

REFERENCES

1. Bertram G, Stickley T. Mental health nurses, promoters of inclusion or perpetrators of exclusion? *J Psychiatr Ment Health Nurs.* 2005;12(4):387-95.
2. Ashwin S, Deb A. Living well with mental illness: findings from India. *J Hum Behav Soc Environ.* 2020:1-8. doi: 10.1080/10911359.2020.1838380
3. Deane FP, Andresen R. Evolution and sustainability of the Helping Hands volunteer program: consumer recovery and mental health comparisons six years on. *Aust. J. Rehabil. Couns.* 2006;12(2):88-103.
4. Singh S, Deshmukh P, Ungratwar A, Subramanyam AA, Kamath R. Does resilience affect illness perception and well-being in the elderly? *J. Geriatr. Ment. Health.* 2014 Jul 1;1(2):94-9. doi: 10.4103/2348-9995.152429
5. Fujiwara T, Yagi J, Homma H, Mashiko H, Nagao K, Okuyama M, Great East Japan Earthquake Follow-up for Children Study Team. Clinically significant behavior problems among young children 2 years after the Great East Japan Earthquake. *PLoS One.* 2014;9(10):e109342. doi: 10.1371/journal.pone.0109342
6. Damsgaard JB, Angel S. Living a Meaningful Life While Struggling with Mental Health: Challenging Aspects Regarding Personal Recovery Encountered in the Mental Health System. *Int J Environ Res Public Health.* 2021 Mar 8;18(5):2708. doi: 10.3390/ijerph18052708.
7. Mental Healthcare Act. 2017. Available from: <https://www.indiacode.nic.in/bitstream/123456789/2249/1/A2017-10.pdf>
8. Jeste DV. Response to the presidential address. *Am. J. Psychiatry.* 2012;169(10):1027-9. doi: 10.1176/appi.ajp.2012.1691002
9. Ralph RO., Corrigan P.W., Nelson G. Recovery in Mental Illness: Broadening Our Understanding of Wellness. *Can. J. Community Ment. Health.* 2009; 28:99–101. doi: 10.7870/cjcmh-2009-0026.
10. Chiu MY, Ho WW, Lo WT, Yiu MG. Operationalization of the SAMHSA model of recovery: A quality-of-life perspective. *Qual. Life Res.* 2010;19:1-13.

11. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry*. 2011 Dec;199(6):445-52. doi: 10.1192/bjp.bp.110.083733
12. Rufener C, Depp CO, Gawronska MK, Saks ER. Recovery in mental illnesses. *Positive psychiatry: A clinical handbook*. 2015:91-110.
13. Benner P. The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In: Benner P (ed.). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. London: Sage Publication, 1994:99-127.
14. Van Manen M. *Researching lived experience: Human science for an action sensitive pedagogy*. 2nd ed. New York: Routledge, 2016, 220. doi: 10.4324/9781315421056.
15. *phenomenological research and writing*. 2nd ed. New York: Routledge, 2023.
16. Slade M, Blackie L, Longden E. Personal growth in psychosis. *World Psychiatry*. 2019;18(1):29.
17. Slade M, Rennick-Egglestone S, Blackie L, Llewellyn-Beardsley J, Franklin D, Hui A, Thornicroft G, McGranahan R, Pollock K, Priebe S, Ramsay A. Post-traumatic growth in mental health recovery: qualitative study of narratives. *BMJ open*. 2019;9(6): e029342.
18. Damsgaard JB, Overgaard CL, Birkelund R. Personal recovery and depression, taking existential and social aspects into account: A struggle with institutional structures, loneliness and identity. *Int J Soc Psychiatry*. 2021;67(1):7-14.

Received on: 02-08-2024

Revised on: 09-09-2024

Accepted on: 21-09-2024

Published on: 21-09-2024