

Lessons Learned From Experiencing Mavi At Café (Blue Horse Café) During Six Years: A Qualitative Analysis of Factors Contributing to Recovery from the Perspective of Schizophrenia Patients



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SUMMARY

Objective: In recent years, the recovery-oriented approaches (along with experiences and thoughts of patients and patient's relatives) have been taken into account for establishing mental health services and policies. This study aims to identify the factors contributing to recovery, as observed from the perspective of schizophrenia patients working at The Blue Horse Café which was founded by the Federation of Schizophrenia Associations.

Method: The sample for the study consisted of 24 patients who worked at The Blue Horse Café. A phenomenological approach was used in the study, whereby interviews with patients were analyzed qualitatively.

Results: Certain common factors, which were expressed as having contributed to recovery, were identified from the perspective of schizophrenia patients. These factors are: 1-The fact that the setting is informal and welcoming without being constrictive; 2-Predominance of the human element; 3-Hope and encouragement; 4-Being cared about; 5-Being able to reach someone when in need of support; 6-Friendly sharing; 7-Having a purpose, assuming responsibility, and being motivated; and 8-Giving meaning to life.

Conclusion: The findings may serve as a stimulus since schizophrenia patients that contribute to recovery give mental health professionals the opportunity to question there need for a change in their professional roles. Additionally, schizophrenia patients that have experienced The Blue Horse Café draw attention to certain points and these points can serve as a guide, especially for establishing the working methods of Community Mental Health Centers.

Keywords: Recovery, schizophrenia, therapeutic community, community mental health

INTRODUCTION

In recent years, the concept of recovery and the adoption of the recovery-oriented approach, (especially in developed countries), has been recognized as a guiding principle for mental health policies. As the main stakeholders in the field of mental health, both mental health professionals along with patients and patient's relatives that use mental health service have started to focus more on the concept of recovery. In their book, "The Roots of the Recovery Movement in Psychiatry,"

Davidson et al (2010) discussed the lessons learned from 300 years of efforts toward considering individuals diagnosed with mental illness as human beings. In particular, the authors acknowledged the quest for better treatment options, and emphasized how the concept of recovery has taken on a new dimension. Amering & Schmolke (2009) drew attention to the changing dimension of the concept of recovery. The "new meaning" of recovery focuses as much on outcome as on process. In particular, it refers simultaneously to agency and interdependency; speaks as much about risk avoidance

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as risk-taking; and moves away from a deficit model toward empowerment, psychological resilience, and hope. The authors also highlight how this new approach to the concept of recovery has transformative implications for mental health services and policies.

The recovery movement took hold in the 1980s. The most important element of this movement was the voice of the user movement (Amering & Schmolke 2009). Successful cooperation between different stakeholders in the field of mental health was only possible by attaching greater importance to research results. These were based on life experiences led and controlled by mental health professionals and service users and by aiming to provide a multi-perspective evidence-base for the production of mental health policies (Rose et al 2006).

Furthermore, successful cooperation between different stakeholders should aim to contribute to the growth and recognition of “a civil rights movement dedicated to the liberation of people with mental illness from being marginalized, from being excluded, and from being shunned” (Thorncroft 2006). As emphasized, again by Amering & Schmolke (2009), recovery should be understood as a concrete and practical process whereby individuals in need of care can regain and maintain better control over their lives. There is a general consensus on the fundamental components which are: self-direction, individualized, empowerment, holistic, nonlinear, strengths-based, peer support, respect, responsibility, and hope (Amering & Schmolke 2009).

The path to recovery can be a highly variable and individual process. Indeed, the process itself is considered to be a component of recovery. Research based solely on groups of subjects and statistical relationships can only be of limited value. Studies on this subject must be supported by scientific procedures that take into consideration the individual experiences of people. As highlighted by Anthony et al. (2003), quantitative methods can only be used sensibly once and qualitative methods have shed light on the impact of complex treatments and on how the transformation takes place.

There is strong evidence as to how relationships and the nature of the milieu play an important part in recovery. This includes both the psychotherapeutic processes and all types of supportive interventions. Recent studies investigating therapeutic milieus and relationships using appropriate methods in psychiatric research appear to be promising (Priebe & McCabe 2006, Amering & Schmolke 2009). “Specific approaches and experimental methods are necessary to ensure that psychiatric services, which want to measure up to recovery parameters, can satisfy the criteria of evidence-based practice”. In this context, it is important that we listen to what mental health service users or patients have to say. This study aimed to identify the factors contributing to recovery, as observed

from the perspective of schizophrenia patients working at The Blue Horse Café.

METHOD

The Milieu

Blue Horse Café was founded in 2009 in Ankara by the Federation of Schizophrenia Associations (FSA) as a therapeutic community and supported-employment setting where schizophrenia patients work. Almost all of the services offered by the café are performed by patients in coordination with a patient relative and a service-industry worker. These services include preparing food and drinks that are served, taking reservations, serving tables, dishwashing, cleaning, organizing meetings, and selling secondhand goods. The Blue Horse Café is an independent institution and receives no support from the state. However, it derives strength from the FSA that also provides financial aid when needed. The café operates according to the main principles of the concept of therapeutic community. It is here that, patients, their relatives, volunteers, mental health professionals, doctors, and “customers” share an equal and democratic environment (Soygür 2011). While the café receives customers from nearly all segments of the population and all ages and genders, the university students are the predominant customers.

The Sample

A qualitative research design was employed in this study and the researchers selected the sample group. This method, called purposive sampling, is a non-probability sampling technique and is widely used in qualitative research (Marshall & Rossman 2006). The sample for the study consisted of 24 out of 30 patients that worked at Blue Horse Café between June 9, 2009 and June 9, 2015. Sixteen of these presently work The Blue Horse Café and 8 have started working at other establishments. Six patients quit their job at the café (2 of them did not want to work and 4 patients moved to other cities and were not included in the research. Of the patients that continued to receive therapy and follow-up care at different centers in Ankara, 9 were women and 15 were men. The mean age was 36.6 (24-55) and the mean duration of illness 18.2 (7-30) years. Two patients lived on their own, 1 lived with their spouse and children, and the other with their families. Informed consent was obtained from all participants.

The interviews took place over the past year and lasted for a minimum of 20 minutes to a maximum of 90 minutes, sometimes with interruptions.

Data Collection Tools

The type of qualitative research design used in the study was the phenomenological approach. We chose to use qualitative

interviewing because the aim of this technique was to collect data that reflected the thoughts, views, and experiences of the individuals forming the sample as comprehensively as possible (Kuş Saillard 2010). Therefore, this allowed both the researchers and the individuals forming the sample to go back and forth in time within the context of reconstructing the past, interpreting the present, and predicting the future.

Qualitative research methodology acknowledges that the researcher plays a subjective role. Nevertheless, in order to ensure credibility, researchers were expected to share the entire research process with readers in a self-reflexive way (Kuş Saillard 2010). The self-reflexive account of the primary researcher that also conducted the interviews in this study is presented below.

Self-Reflexive Account Of The Primary Researcher

The primary researcher was a doctor who chose to specialize in psychiatry after graduating from medical school. He worked at every level in this field for approximately 30 years and has dealt with schizophrenia patients for a significant portion of this time. He has been actively involved from the beginning in the non-governmental organization (NGO), which schizophrenia patients and their relatives established together with mental health professionals in Turkey. The researcher also took part in the founding of The Blue Horse Café where schizophrenia patients work and the research samples selected. The main motive for the study came from the subjective experiences emerging from the semi-professional relationship he has had for many years with schizophrenia patients and their relatives. In this sense, the researcher has taken “a position both inside and outside”. He has witnessed and embraced the motto “don’t ask the doctor, ask the one who suffers” and has taken the perspective of schizophrenia patients and their relatives. In addition, he has shared the process and has become closely acquainted with his patients. His role as both as an NGO activist and academician gives a subjective position in the processes of topic selection and treatment.

Interview Question

The face-to-face interviews began with an open-ended question: “How has working at The Blue Horse Café contributed to your process of recovery?” The main aim of the researchers was to collect as much information as possible about factor that played a part in the recovery process. With the aim of capturing the thoughts and experiences of participants in a more comprehensive manner, the researchers further refined the main question along two main themes and occasionally asked them to “elaborate” or “give examples”. These themes were: How participants spent their daily lives and the content of their relationships.

Analysis of The Data

Interviews were recorded and transcribed and the transcriptions were imported into Nvivo version 10, a software for qualitative data analysis. Simultaneously, the research team read all transcribed data and noted texts that were relevant to the theme of factors effective in recovery. Summaries were developed inductively and discussed with the entire team. The analysis was performed using these two methods, thereby increasing credibility. The categories identified were used to generate themes related to recovery.

RESULTS

From the perspective of schizophrenia patients, the factors they believe contribute to their recovery by working at The Blue Horse Café were grouped under the following categories:

1-An Environment That Is Informal And Welcoming Without Being Constrictive

When talking about the environment, participants emphasized its informality and how it does not remind them of hospitals or other health institutions, and chose words such as harbor, fortress, and shelter when making comparisons. The points most emphasized by the participants were the fact that those in the environment shared the same feelings and that everyone sharing the environment, including mental health professionals, had a genuine, equal, power-sharing, and cooperative attitude. The following words of one of the patients are a concrete example of the power-sharing and cooperation in the environment: *“Nobody looks down on anybody here. Of course there are rules, but we are all equal and valuable. We all have a say. No one puts on airs of superiority. Come to think of it, even the doctors who visit here behave differently.”* Another patient described how the environment gives them strength as follows: *“I’m worried that The Blue Horse might close. I’ve been here for so many years. This is my harbor. That’s not to say that I’ve anchored in the harbor and am waiting to rot. I am nourished by this place and open up to the outside world. This place gives me strength.”* Another patient described how the environment is supportive without being constrictive as follows: *“It’s not like a government office here, it’s not cold. I mean there’s sincerity. We’re always together. If I want, I can also withdraw to a solitary corner. No one will say anything. At some point they’ll come and ask what’s wrong. And later I’ll join them.”* Participants said that their repertoire of social behaviors had expanded and that they communicated not just with those who worked in or came to the café but also with local shop owners in the area and neighbors in the building. One participant stated that **“they had previously participated in social skills training groups at the day hospital, that this**

had also been beneficial, but that here they felt like they were “practicing”, that they were a part of life.”

2-Predominance of the Human Element

Participants emphasized that relationships with health care professionals, especially in hospital or polyclinic settings, were cold, indifferent, or lacked sincerity, because they were only concerned with doing their job. By contrast, they drew attention to the humanistic aspects, sincerity, and respect and equality-based aspects of the relationships in the café environment. The contribution to recovery of human-to-human relationships mentioned by many patients is illustrated in the most striking manner in the following account by a patient: *“Here, I feel that they truly care about me, that they listen to me. You are human too; you can feel how people treat you. In the hospital, it’s just two minutes and they don’t even ask your name. I don’t think they’re much concerned about me either. It’s like they treat you like you’re a nobody. It’s different here! Here, I feel the sincerity and warmth and it does me a lot of good. Without sincerity one cannot talk about oneself. It’s the human side that’s important before all else. I mean before the medical stuff and all.”*

3-Hope and Encouragement

“I thought it was all over. I failed at school, failed at life. I was just vegetating along. I can’t begin to tell the feelings that emerged when they tried to instill hope in me. The fact that this place exists gives me courage. Sometimes it can be really difficult, but I believe that everything is going to be better.

Participants stated that when they were faced with a challenge and had difficulty getting on with their life. They derived strength from patients, patient relatives, volunteers, or mental health professionals. In addition, their active or passive presence renewed their hopes and encouraged them. They expressed that in the process, their self-confidence grew, and, that being able to do a job, succeeding, and being appreciated for what they did fostered this feeling.

4-Being Cared About

Participants expressed their gratitude for being “cared about and being taken seriously” when they felt the need for assistance in their relationships in the milieu and gave examples pertaining to this: *“When my mother became ill my greatest fear was losing her. In the end it happened, and my mother died. The people here were there for me, both when my mother was ill and when I lost her. They all helped me out; some phoned me to remind me to take my medicine, others brought me soup. After my mother died, both my older sister and older brother moved to another city and asked me to join them. I really struggled with the decision but*

ended up staying. Now I live alone, and I know that I have a family here too.

“While I was working here I took the civil service exam for persons with disabilities and I passed. I was so happy when they congratulated me and gave me presents.”

5-Being Able to Reach Someone When in Need of Support

Laying particular stress on the importance of being able to reach someone they could trust in situations where they felt they needed immediate help or in crisis situations. The participants pointed out how valuable it was for them to have been able to even just reach someone at such times. One patient described their experience in this regard as follows: *“Getting help from others when you are truly in need of help is a wonderful thing. Previously, (now I think differently) I would cut down on my medication on my own initiative at every opportunity. Now, when I think back, I realize that whenever I did so my mind would immediately start to get confused, my sleep would get worse and my anger would grow. I would start suspecting everyone. On one such day, those at the café realized what was going on and warned me. I didn’t listen. That night they called me. The doctor also called. We talked at length. Later, I started taking my medication again. My condition quickly improved. I don’t remember how many times this repeated. Every time, they patiently tried to help me. I think that now I’m aware of the situation. I believe I’m really lucky to be able to reach them and to have them at my side.”*

6-Friendly Sharing

Participants stated that the café’s atmosphere of friendship was very valuable to them and shared that this did not consist only of relationships with peers but that they had similar experiences with patient relatives, volunteers, and mental health professionals as well. One patient described the benefits of friendly sharing in relationships as follows: *“I wish we could talk and share like this with the doctors at the hospitals where I go! It wouldn’t make them less important or anything; on the contrary, we would think much more highly of them. I wonder, do they believe that if we have a friendly relationship we will treat them disrespectfully or something? Or that we will cross the line?”*

7-Having a Purpose, Assuming Responsibility, and Being Motivated

Participants expressed their contentment in having a purpose and bringing order to their lives. They had achieved a kind of self-discipline that they felt a desire to do work, and wanted to be neat and well-groomed when going to the café. One participant described the order restored to their life as follows:

"This place has helped me wind the clock inside me." Participants reported that having people ask to be served and being able to meet their requests, learning new things and being useful, and having a purpose is gratifying. *"Working is like worship. It makes one happy to grasp certain things, achieve results, bring a number of things together and, from there, unfold many her things." "I liked it that people who came here asked me to serve them... At first I got excited. Later I got used to it. My hands used to shake. The tea would almost spill. Now I'm really good at it."*

Many participants expressed their contentment in being given responsibility for various matters and stressed that this helped them move away from seeing themselves as passive or ill: *"It is really important to me that people trust me and give me responsibility. It makes me feel like I'm not ill. Something I hadn't felt in a long time."*

"I feel like if I weren't there no one else could do my job. When I serve people at their table they thank me, and it's me who is doing it."

8-Giving a Meaning to Life

Participants said that being at the café added meaning to their lives and saved them from monotony.

"The sameness and monotony of life is over for me. They do something every day here."

"I believe that it's the meaning of life for me too. Previously a doctor asked me what the meaning of life was for me. I wasn't able to answer. Now, I say it's working here, my friends and all. I too have a reason for waking up in the morning."

DISCUSSION

The findings obtained from this study explored factors that contribute to the path to recovery from the perspective of schizophrenia patients working in The Blue Horse Café environment. In addition, these findings are similar to the results of previous research on recovery and rehabilitation that emphasize the need for human elements and strong collaboration among all stakeholders in the field of mental health (Onyett 1992, Topor 2001, Sells et al. 2004, Davidson et al. 2003, Borg & Kristiansen 2004, Schon et al. 2009). Conversely, the present study showed that none of the individuals sharing the environment studied brought their full professional identity to the setting. It was not just the semi-professional efforts of mental health professionals, but also those of other patients, patient relatives, volunteers, and people that were in touch with the café that played a part in making factors believed to contribute to recovery become possible. What this means is that the factors that patients believe contribute to

recovery as regards relationships in the milieu should not be overlooked in professional settings or in the practice of psychiatry. Although the findings obtained may not be findings that have been identified for the first time, they show how certain factors are valuable in the eyes of the patients and are perceived as beneficial.

Being a recovery-oriented mental health professional means embracing a new approach whereby the relatively narrow boundaries of traditional service delivery are at least challenged. In addition, efforts are made toward adopting an approach that gives priority to the needs and preferences of patients. No doubt that the knowledge and experience of experts in the field of mental health are an essential element in the path to recovery. Being recovery-oriented is a term for not settling for specialist knowledge and experience alone. However, attempts at coordination and cooperation, sharing power with the affected persons themselves, and attaching importance to the wisdom and insights born of their experiences is also important. Recovery is a process in which the affected individual actively participates. The task of professionals is to discover and support the individual's capacity toward recovery by adopting a patient- rather than illness-centered perspective. We should not forget that this process is one "where competence and knowledge are developed and tried out in a joint venture," with the contribution of everyone involved along the way (Borg & Kristiansen 2004).

Lambert (1992) states that specific treatment techniques account for only 15% of recoveries. Tallman & Bohart (1999) have shown "that the quality of the therapeutic relationship is the best predictor of outcome" in the recovery of people with mental health problems. Sells et al (2003) researched the conditions in which it was possible for patients to perceive mental health professionals as supportive, and arrived at the following conclusions: 1- that mental health professionals create and develop a collaborative attitude dedicated to the individuals seeking help; 2- that they focus on the inner resources of the affected person and give priority to establishing a constructive and positive relationship with that person; 3- that they do not restrict themselves to the symptoms and deficits of the illness; and 4- that they maintain a rational optimism. Despite the results obtained in these studies, medication and treatment programs are considered to be "real" and "important," factors related to milieu and therapeutic relationship. These are generally scorned and to quote Borg & Kristiansen (2004), "reduced to a 'nice but not necessary' humanistic phenomenon." The present study even more thoroughly supports the importance of the nature of milieu and of relationships.

The long-standing debate as to whether schizophrenia is an illness from which one never fully recovers and ends with cognitive deterioration, or whether it is an illness whereby different levels of recovery can be achieved, is outside the boundaries of this study. However, there is the inescapable fact that

adopting either a pessimistic or optimistic perspective toward the course and outcome of schizophrenia does influence the relationship established with patients. Despite the promising results of many studies that show that recovery is possible (Strauss 1989, Strauss 1992, Harding & Zahnister 1994, Harrison et al 2001, Davidson 2003), there are a considerable number of mental health professionals who favor traditional psychiatry and are at the pessimistic end of the spectrum. In the final analysis, the factors that participants in the present study believe contribute to recovery show the need for a respectful relationship between equals. To quote Borg & Kristiansen (2004), who cite Martin Buber (1986), the relationship between helper and service user is an action to which both parties actively contribute, and what is essential in this relationship “is not what is inside each individual, but what is created between them.” This mutual relationship involves seeing the affected individual as “capable and resourceful.” Mental health professionals who have a traditional psychiatric perspective run contrary to this point of view in that they believe that in schizophrenia, the subjectivity and inner life of the individual is chronically disturbed and that the illness takes a negative course. The biggest obstacle standing in the way of establishing a respectful relationship between equals seems to be the pessimistic perspective of professionals who perceive the person they are trying to help as the miserable, passive victim of a chronic and devastating illness, and believe that there is nothing they can do other than relieving the symptoms. At the same time, this is a barrier to the matters of hope and encouragement on which participants have laid special emphasis. We cannot expect a mental health professional who has no expectation for the recovery of, nor hope for a better life for the person they are trying to help to give hope to a person in such great distress. Yet, as Glover (2002) says, the most important element in how mental health professionals define their role is their being hopeful and being able to convey this hope.

The findings of this study should serve as a stimulus for two reasons in particular. The first is that the factors that schizophrenia patients believe contribute to recovery give mental health professionals the opportunity to question whether there is need for a change in their professional roles. The principal feature of this questioning is that human qualities emerge as an element that is “more important than academic titles, professional background, or concrete therapeutic modalities and techniques” (Amering&Schmolke 2009). Once mental health professionals and patients are “ready and able to show their human sides” and once they have the courage to act as themselves, the therapeutic relationship can become more beneficial. Having people open their hearts to each another makes collaboration and partnership possible. The second reason is of particular importance at a time when efforts are being made in Turkey to implement

community-based mental health services for schizophrenia patients and there is need for a recovery-oriented approach. Schizophrenia patients who have experienced The Blue Horse Café draw attention to certain themes in reference to factors contributing to recovery. These themes can serve as a guide, especially for establishing the working methods of Community Mental Health Centers. As long as mental health services are confined to general medical services the way they are at present, they cannot be sufficiently effective. It seems that the background and skills of the mental health team working in these centers need to be shaped in line with the highlighted themes. Mental health services in which human elements are brought to the highest level and are offered in environments that are flexible, genuine, and as informal as possible will greatly contribute to recovery.

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