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Satisfaction of Patients and Their Relatives Who Are Reminded of Their Appointments and Treatments with "*Treatment Collaboration Portal*"

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ABSTRACT

Background: Community Mental Health Centers have been established in Turkey for patients with chronic psychiatric disorders actively engaged in treatment. The Treatment Collaboration Portal is a web-based voice response platform offered to Community Mental Health Centres to support the treatment compliance processes of patients. The Treatment Collaboration Portal automatically reminds patients or their families of injection treatments and psychiatry appointments at regular intervals. The purpose of this study is to determine the satisfaction of patients or their relatives enrolled in the Treatment Collaboration Portal and the reasons why.

Methods: A semi-structured 1-item 6-point satisfaction questionnaire, which we prepared for the Treatment Collaboration Portal reminder calls, was administered to the volunteer participants who registered to the Treatment Collaboration Portal and Community Mental Health Centre. Satisfaction levels were determined first with the questionnaire, and then the reasons for satisfaction were investigated for each patient and their relatives.

Results: The questionnaire was given to 132 participants. About 121 participants were satisfied and 11 of them were dissatisfied. When the reasons for those who were satisfied with the application reminders were examined, it was seen that the most frequent one was "prevention of forgetfulness" (53.7%). A significant difference was found between the Treatment Collaboration Portal registration reasons and satisfaction status. Also, there was a difference between the people who patients live with and the "satisfied" and "unsatisfied" groups ($P = .023$).

Conclusion: All the reasons given by the group satisfied with Treatment Collaboration Portal use contribute to patients remaining in remission. Therefore, in clinical practice, it is very important to recognize these reasons.

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INTRODUCTION

Severe and chronic psychiatric disorders, such as schizophrenia, significantly impair functionality and are associated with increased mortality and morbidity.[1] S Multiple meta-analyses consistently report a significant reduction in life expectancy, estimating an approximate loss of 15 years in individuals diagnosed with schizophrenia.[2-4] The prevalence of disability in schizophrenia is 0.4%.[5] The high rates of disability in schizophrenia patients are attributed to the chronic course of the disease and factors such as cognitive impairment, as well as frequent treatment noncompliance.[6,7] The treatment gap remains disparate in developing and underdeveloped countries.[8,9] Even when there is available treatment, adherence to antipsychotics is low due to patients' lack of insight into the disease, their forgetfulness resulting from cognitive impairment, and the adverse effects of the treatment.[10] Treatment adherence is defined as the patient's use of not only psychopharmacological agents but also the implementation of all other treatment recommendations, such as regular follow-up visits and compliance with behavioral recommendations. In the course of chronic psychiatric disorders, the patient needs to be seen and examined on regular follow-up appointments. Clinic appointments are an opportunity for patients to receive advice and monitoring regarding their psychological and general medical condition.[11] Psychiatric patients often delay their follow-ups due to forgetting their appointment dates.[12] For this purpose, WHO's Mental Health Gap Action Programme has identified schizophrenia as a global concern of high priority, recommending treatment with a

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combination of antipsychotic medication and psychosocial care.[13] As a result, there is a general agreement in favor of collaborative care, which emphasizes community and family-based treatment, and integrating mental healthcare into existing primary care.[9,13,14] In order to fill this gap, Community Mental Health Centers (CMHC) were recently established in Turkey to keep patients with severe mental disorders such as schizophrenia and bipolar disorder under active surveillance and treatment by providing basic psychosocial support. In this regard, the most important thing is reminding patients and/or their relatives registered with CMHC of routine follow-ups and treatments such as monthly injections.

The Treatment Collaboration Portal (TCP) is a web-based platform and Interactive Voice Response System. It was made available to hospitals and CMHC in 2010 to improve treatment adherence for schizophrenia patients. The system, which began on March 1, 2010, with the first calls totaling 400 records in 5 centers, has reached 78 centers and a total of more than 11 000 records by October 2020, and the overall call response rate is 67%. The contact numbers of patients and their relatives are recorded in this system by CMHC after obtaining their consent. This personal information is stored encrypted with 128-bit SSL. All calls are made on behalf of the centers themselves. Each center will receive a special link and password for TCP. The responsible physician/nurse can securely access the portal from any computer with an Internet connection using the given credentials. The doctor/nurse in charge sets the reason for the appointment, such as "routine follow-up, injection, therapy, family education, blood analysis," stores the reminders with their data in the portal, and ensures that they are sent via the cell phone answering system. The system automatically reaches the person registered in the portal in the form of a recorded voice message 2 days before the appointment as a reminder. Two days after the appointment, the contact number is automatically called again. If the appointment was kept, the contact person is asked to press number 1 on the keypad, if not, number 2. The responses entered are automatically recorded by the system. In this way, patients who have not kept their appointments can be tracked down and treatment can be completed without further loss of time.

Since the start of active use of the portal, the number of in-person calls made by CMHC teams to follow up with patients has decreased significantly and the workload has decreased. Having team members do their daily work through a more systematic and regular platform like this saves time and reduces the possibility of disruptive or repetitive tasks. To our knowledge, there is no web-based system similar to the TCP for patient care and appointment tracking in CMHCs in Turkey. This study is the first in our country. Our aim was to determine the level of satisfaction of patients and/or their relatives registered in the TCP with the voice response system by reminding them of injections and appointments and to investigate the reasons for their satisfaction or dissatisfaction. We also investigated the relationship between the level of satisfaction and patients' sociodemographic and clinical characteristics.

MAIN POINTS

- Treatment Collaboration Portal is a web-based system used for follow-up of treatment and appointments of patients with psychosis and bipolar disorder who registered with Community Mental Health Centre. In our study, we found that patients and their families were very satisfied with the Treatment Collaboration Portal.
- When the reasons for the satisfaction of the participants were investigated, feedback such as preventing them from forgetting the treatment, decreasing the caregiver burden, increasing compliance to treatment, and increasing the possibility of retreatment in recurrence were obtained.
- We believe that the reasons cited by those who are satisfied with Treatment Collaboration Portal can reduce relapses.

MATERIAL AND METHODS

Participants

Patients with psychiatric disorders and their relatives registered with TCP were included in our study. The ethical committee of Ankara Oncology Training and Research Hospital approval was received on October 7, 2020 (Approval Number: 2020-10/80). All patients and/or their relatives registered in the portal, who were contacted through the telephone numbers registered in the outpatient clinic or in the portal, gave their informed consent after the study was explained to them in detail during their visit to the outpatient clinic. Sociodemographic characteristics such as age, gender, marital status, employment status, occupation, and clinical histories such as duration of untreated psychosis, treatments used, and comorbidities were documented using a form prepared for the study. Participants were given a 6-point satisfaction questionnaire (very satisfied, satisfied, less satisfied, not satisfied, uncomfortable, and very uncomfortable) prepared for the TCP reminder calls. It consisted of only 1 question. We also asked participants their reasons for satisfaction or dissatisfaction. This question was an open-ended question. Then, the reasons for satisfaction or dissatisfaction were examined for each participant. These reasons were then divided into subcategories.

Statistical Analyses

Data were analyzed with Statistical Package for the Social Sciences (SPSS) version 23.0 (IBM SPSS Corp.; Armonk, NY, USA). The conformity to the normal distribution was examined using the Shapiro-Wilk *U* test. Mann-Whitney *U* test was used to compare the data that were not normally distributed between independent groups.

The Fisher–Freeman–Halton and Fisher's exact tests were used to compare categorical data, and multiple comparisons were examined with Bonferroni corrected *Z* test. Results were presented as frequency (percentage) for categorical data and as mean ± SD and median (minimum-maximum) for quantitative variables. The significance level was taken as $P < .050$.

RESULTS

There were 169 people (patients and/or their relatives) who were registered with the TCP. We tried to reach these registered people (by phone or face-to-face) for research. Of the patients and/or their relatives who attempted to be reached by telephone, 22 (13%) did not respond, 6 (3.55%) telephone lines were canceled, and 6 (3.55%) of them were incorrectly registered with the TCP. Three patients (1.8%) indicated that they were not called by the TCP and therefore could not answer the questionnaire. Therefore, 132 (78.1%) volunteers were included in the study. Of the 132 volunteers whose satisfaction status was queried, 121 (71.6%) indicated that they were satisfied (very satisfied, satisfied, and less satisfied), and 11 (6.5%) of them were dissatisfied (not satisfied, uncomfortable, and very uncomfortable). The participants were divided into 2 groups according to their satisfaction. These groups were the "satisfied group" and the "dissatisfied group." We included those who answered the questionnaire as "very satisfied, satisfied, less satisfied" in the "satisfied group," and those who answered "not satisfied, uncomfortable, very uncomfortable" in the "unsatisfied group."

Considering the satisfaction rates of the participants, the highest rate was obtained from those who were very satisfied at 63.6%, and the lowest rate of those who were uncomfortable at 0.8%. Considering the reasons, the highest rate was 53.7% for preventing of forgetfulness, while the lowest rate was 0.8% for a positive effect on the patients and their relatives close relationship. While 66.7% of the participants were female, 33.3% were male. The rate of enrollment for long-acting injections was 34.8%, the rate of appointments was 39.4%, and the rate of both was 25.8%. The highest rate of satisfaction for the appointment was very satisfied with 79.1%, and the lowest rate was obtained as less satisfied with 4.7%. The rate of those diagnosed with schizophrenia was 93.2%, the rate of those with bipolar disorder was 4.55%, the rate of those with schizoaffective disorder was 1.5%, and the rate of those with delusional disorder was 0.75%. While the highest rate of education is mid-high school with 40.2%, the lowest rate belongs to literate with 0.8%. The rate of those whose marital status was single was 59.1% and the rate of those who were married was 28.8%. The rate of employees was 14.4% and the rate of those who did not work was 85.6%. The highest rate was found in the people living with their parents at 50%, and the lowest rate was obtained in the other category at 2.3%. Looking at monthly earnings, 12.9% of people have income less than 2000 TL, 73.5% between 2000 and 5000 TL, and 13.6% of people with 5000 TL or more income. The rate of those with additional medical diseases was 23.5% (Table 1).

Table 2 shows the comparison of the satisfied and the dissatisfied groups with sociodemographic characteristics. A statistically significant difference was found between the distribution of the people with whom the patients lived according to their level of satisfaction ($P = .020$). The difference here is due to the fact that the proportions of those living with their parents and those living with their siblings are different. While the rate of those who are satisfied with their parents is 52.9%, the rate of those who are not satisfied is 18.2%. While the rate of those who are satisfied with their siblings is 6.6%, the rate of those who are not satisfied is 36.4%. Other variables do not differ according to satisfaction ($P > .050$).

Table 3 shows the comparison of the satisfied and the dissatisfied groups with the other sociodemographic characteristics. A statistical difference was found between the distribution of reasons for enrollment according to satisfaction ($P = .003$). The reason for the difference in registration here is due to the distribution of long-acting injections and appointments. While the rate of those who were satisfied with the system in regard to LAI reminders was 30.6%, the rate of those who were not satisfied was 81.8%. The rate of satisfaction among those who registered with the system for the purposes of appointment reminders was 42.1%, while the rate of those who were not satisfied was 9.1%. Other variables do not differ according to satisfaction ($P > .050$).

DISCUSSION

Despite differences in sociodemographic and clinical variables in the analyses, most participants were satisfied with the TCP. The reason for enrollment in the system and the people with whom the patient lived appeared to influence satisfaction. Those who had registered for injection reminders were less satisfied. It was also found that those who lived with their parents were more satisfied, while those who lived with their siblings appeared to be less satisfied.

It was surprising to see that the satisfaction of those who registered to TCP for long-acting injection follow-ups was lower and the satisfaction of those who registered to TCP for an appointment was higher. This can be connected to a sense of pressure to get the treatment that patients might feel. It has been reported that perceived or real coercion at any point in injectable drug treatments impairs the therapeutic relationship.[15-17] In other words, unsatisfied participants may have perceived TCP reminders as a compulsion that might create an uncomfortable feeling. Alternatively, the physical discomfort of using injectable

Table 1. Frequency Distribution of Variables

	n	%
Satisfactions		
Very Satisfied	84	63.6
Satisfied	30	22.7
Less satisfied	7	5.3
Dissatisfied	6	4.5
Uncomfortable	1	0.8
Very uncomfortable	4	3
Satisfaction reasons		
Preventing forgetfulness	65	53.7
Feel cared for	25	20.7
Reduction in care burden	11	9.1
Compliance to treatment	11	9.1
Consciousness for disorders	3	2.5
Retreatment at relapses	2	1.7
Patient-relatives relationship	1	0.8
Quality of life	3	2.5
Gender		
Female	88	66.7
Male	44	33.3
Registration reasons		
Long-acting injection	46	34.8
Appointment	52	39.4
Both of them	34	25.8
Satisfaction for appointment		
Very satisfied	68	79.1
Satisfied	14	16.3
Less Satisfied	4	4.7
Diagnosis		
Schizophrenia	123	93.2
Bipolar disorder	6	4.55
Schizoaffective disorder	2	1.5
Delusional disorder	1	0.75
Education		
Illiterate	4	3.0
Literate	1	0.8
Primary school	20	15.2
Junior high school	24	18.2
Mid-high school	53	40.2
Senior high school	20	15.2
University	10	7.6
Marital status		
Single	78	59.1
Married	38	28.8
Widow	2	1.5
Divorced	14	10.6

(*Continued*)

Table 1. Frequency Distribution of Variables (*Continued*)

	n	%
People who patients live with		
Parents	66	50
Family	25	18.9
Partner	13	9.8
Sibling	12	9.1
Alone	13	9.8
Other	3	2.3
Working		
Yes	19	14.4
No	113	85.6
Satisfaction for appointment		
Very satisfied	68	79.1
Satisfied	14	16.3
Less satisfied	4	4.7
Enrolled person		
Patients	47	35.6
Patient's relatives	85	64.4
Kinship		
Parents	19	22.4
Family	15	17.6
Partner	26	30.6
Sibling	15	17.6
Alone	6	7.1
Other	4	4.7
Monthly income		
<2000	17	12.9
2000-5000	97	73.5
>5000	18	13.6
Comorbid medical illness		
Yes	31	23.5
No	101	76.5

antipsychotics may be projected as dissatisfaction. Visits of patients in remission are likely to be performed every 4 or 5 months. Except for the 3-month long-acting injection of paliperidone, most other long-acting injections are given almost every month. A date longer than a month is more likely to be forgotten. The fact that appointments given to patients in remission are usually longer than 1 month may have increased the likelihood of appointments being forgotten. Patients or their relatives may remember an injection more easily on a certain date of each month or on a certain day every 3 or 4 weeks. In any case, more compliant patients and their relatives who want to come to their appointments regularly may have been more satisfied with these reminders.

In examining the relationship between the "satisfied group" and the "dissatisfied group" and the people with

Table 2. Comparison of the Satisfied and the Dissatisfied Groups with Sociodemographic Characteristics

	The Satisfied Group (n=121)	The Dissatisfied Group (n=11)	Total (n=132)	*P*
Gender				
Female	81 (66.9)	7 (63.6)	88 (66.7)	**1.000***
Male	40 (33.1)	4 (36.4)	44 (33.3)	
Education				
Illiterate	4 (3.3)	0 (0)	4 (3)	
Literate	1 (0.8)	0 (0)	1 (0.8)	
Primary school	20 (16.5)	0 (0)	20 (15.2)	
Junior high school	23 (19)	1 (9.1)	24 (18.2)	**.364****
Mid-high school	48 (39.7)	5 (45.5)	53 (40.2)	
Senior high school	17 (14)	3 (27.3)	20 (15.2)	
University	8 (6.6)	2 (18.2)	10 (7.6)	
Marital status				
Single	71 (58.7)	7 (63.6)	78 (59.1)	
Married	34 (28.1)	4 (36.4)	38 (28.8)	**.652****
Widow	2 (1.7)	0 (0)	2 (1.5)	
Divorced	14 (11.6)	0 (0)	14 (10.6)	
Working				
Yes	17 (14)	2 (18.2)	19 (14.4)	**.659***
No	104 (86)	9 (81.8)	113 (85.6)	
People who patients live with				
Parents	64 (52.9)[a]	2 (18.2)[b]	66 (50)	
Family	23 (19)[a]	2 (18.2)[a]	25 (18.9)	
Partner	11 (9.1)[a]	2 (18.2)[a]	13 (9.8)	**.023****
Sibling	8 (6.6)[a]	4 (36.4)[b]	12 (9.1)	
Alone	12 (9.9)[a]	1 (9.1)[a]	13 (9.8)	
Other	3 (2.5)[a]	0 (0)[a]	3 (2.3)	
Monthly income				
<2000	16 (13.2)	1 (9.1)	17 (12.9)	
2000-5000	90 (74.4)	7 (63.6)	97 (73.5)	**0339****
>5000	15 (12.4)	3 (27.3)	18 (13.6)	
Comorbid medical illness				
Yes	29 (24.2)	2 (18.2)	31 (23.7)	**1.000***
No	91 (75.8)	10 (81.8)	101 (76.3)	
Age	42 (23-70)	40 (35-62)	42 (23-70)	**.951*****

*Fisher's exact test.
**Fisher-Freeman-Halton test.
***Mann-Whitney *U* test.
[a-b]No difference between groups with the same letter; frequency (percentage); median (minimum-maximum).
The significance level was taken as $P < .050$

Table 3. Comparison of the Satisfied and the Dissatisfied Groups with the Other Sociodemographic Characteristics

	The Satisfied Group (n=121)	The Dissatisfied Group (n=11)	Total (n=132)	*P*
Registration reasons				
Long-acting injection	37 (30.6)a	9 (81.8)b	46 (34.8)	
Appointment	51 (42.1)a	1 (9.1)b	52 (39.4)	**.004****
Both of them	33 (27.3)a	1 (9.1)a	34 (25.8)	
Enrollee person				
Patients	43 (35.5)	4 (36.4)	47 (35.6)	**1.000***
Patient's relatives	78 (64.5)	7 (63.6)	85 (64.4)	
Kinship				
Mother	18 (23.1)	1 (14.3)	19 (22.4)	
Father	15 (19.2)	0 (0)	15 (17.6)	
Siblings	22 (28.2)	4 (57.1)	26 (30.6)	**.586****
Partner	13 (16.7)	2 (28.6)	15 (17.6)	
Child	6 (7.7)	0 (0)	6 (7.1)	
Other	4 (5.1)	0 (0)	4 (4.7)	
Satisfaction for appointment				
Very satisfied	66 (78.6)	2 (100)	68 (79.1)	
Satisfied	14 (16.7)	0 (0)	14 (16.3)	**1.000****
Less satisfied	4 (4.8)	0 (0)	4 (4.7)	
Diagnosis				
Schizophrenia	112 (92.6)	11 (100)	123 (93.2)	
Bipolar disorder	6 (5)	0 (0)	6 (4.5)	**1.000****
Schizoaffective disorder	2 (1.7)	0 (0)	2 (1.5)	
Delusional disorder	1 (0.8)	0 (0)	1 (0.8)	
TCP admission times	24 (1-34)	30 (9-33)	24.5 (1-34)	**.276*****
CMHC admission times	49 (0-61)	41 (19-60)	48 (0-61)	**.589*****
DUP	5 (0-84)	9 (1-84)	6 (0-84)	**.085*****

*Fisher's exact test.
**Fisher Freeman Halton test.
***Mann-Whitney *U* test.
[a-b]No difference between groups with the same letter; frequency (percentage); median (minimum-maximum).
The significance level was taken as $P < .050$

whom patients live, we found that the satisfaction of those who live with their parents is high, while the satisfaction of those who live with their siblings is relatively low. There may be several reasons for this difference. Because most patients have schizophrenia, they are unlikely to marry or leave home alone.[18] In addition, it has been reported that the divorce or separation rate is increased in schizophrenic patients, although the most common marital status among these patients was being single.[19] In our country, the number of schizophrenia patients living alone is lower than in most other countries,[20] and it has been reported that most patients with schizophrenia live with their parents.[21] Most schizophrenia patients in our study also live with their parents. When the reasons for those who were satisfied with application reminders were examined, it

was found that the most common reason was "preventing forgetfulness." Parents of adult patients may be more forgetful because they are older than others with whom they live. With reminder calls from the TCP, it is possible that they have overcome these difficulties. It was found that the satisfaction of those who live with their siblings is lower than that of other people who live together. It is possible that reminder calls to siblings living together in the same house may have impaired the patient's autonomy and thus reduced satisfaction.

According to our data, "preventing forgetfulness" was found to be the most common reason for satisfaction. About 53.7% of the participant stated that they were happy to be called this way because it prevented them from forgetting their follow-up and treatment. About 20.7% of the participants stated that they felt cared for and were pleased by this. This shows us how high the expectations of patients and their relatives from mental health professionals are for attention and support.

Several factors affect the caregiver burden in schizophrenia. Examples of these are age, gender, psychological factors, or personality differences. The level of functionality, quality of life, and satisfaction of the caregiver are also effective in the caregiver's burden.[20] Low levels of satisfaction with care can lead to emotional distress, family conflicts, and compromised quality of life.[21] In our study, 9.1% of the participants stated that they were satisfied because it reduced the burden on caregivers and 2.5% of them stated that they were satisfied because their quality of life increased.

Eleven of the participants were dissatisfied or uncomfortable with TCP. When the reasons were explored, 5 participants stated that the system reminded them of the injection times and dates incorrectly. One of the patients stated that the reminders were for her husband and she was uncomfortable with the calls because they were currently in divorce proceedings. Another patient had just been diagnosed with cancer and did not want to deal with calls at that time. A relative of one patient reported that he could not convince his patient that he was being called to remind him of the injection and provided feedback that it would be better if the calls were directed to himself as well as to his patient. Of the other 3 patients who reported not being satisfied, one of them was startled by the ringing of the phone, the other reported that the voice of the message was very artificial and robotic, and the other reported that these calls made him feel inadequate.

Some of the individual reasons for dissatisfaction or discomfort with the application were related to the timing of the calls. Treatment Collaboration Portal reminds patients of their appointments 2 days before the appointment. Then, 2 days after the appointment, a call asks patients and/or their families whether they attended the appointment (press 1) or not (press 2). The fact that these 2 calls occurred 2 days before and 2 days after the appointment may have been confusing to some participants.

Treatment noncompliance is common in severe psychiatric disorders. Treatment non-compliance includes problems with taking medications, keeping regular appointments, and following behavioral recommendations. About 9.1% of the group who reported that they were satisfied with the calls indicated that they were satisfied because this use strengthened the patient's compliance with treatment. About 1.7% of participants indicated that they were satisfied with TCP because it increased the possibility of re-treatment after relapse, and 2.5% of participants indicated that they became more aware of it. This can be interpreted to mean that the TCP may have increased treatment adherence. The efficacy of such practices on treatment compliance needs further investigation.

To the best of our knowledge, this study is the first to investigate the effects of TCP, currently used in a few centers in Turkey, on patients and their relatives. Chronic psychiatric diseases and schizophrenia are disorders that significantly impair functionality and greatly increase long-term mortality, morbidity, and disability rates. For this reason, it is important to systematically remind patients and/or their families of necessary treatments and appointments. All the reasons mentioned by the satisfied group with TCP will help to keep the patients in remission, reduce the fluctuations in the chronic course of the disease, and decrease the disability rate. However, our study has limitations. We were only able to reach a sample of patients enrolled in a single CMHC database. Our sample size is small. Because of the COVID-19 pandemic, our questionnaire was completed primarily via telephone calls. Whether on the phone or face to face, personal interaction may have made it difficult for participants to express their true feelings, which may have led to bias in our data. In addition, not using a standardized satisfaction questionnaire may have decreased the reliability and comparability of our results. Nevertheless, we believe that most CMHC staff likely recognize the positive impact that a good relationship with patients and their families has on treatment adherence.

Ethics Committee Approval: This study was approved by Ethical Committee of Ankara Oncology Training and Research Hospital (Approval No: 2020-10/801, Date: October 7, 2020).

Informed Consent: Written informed consent was obtained from the participants who agreed to take part in the study.

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