SCHIZOPHRENIA: LIVING WITH OR AGAINST THE ILLNESS. A SMALL CASE EXPLORATORY STUDY[1]

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Abstract: ***Background:*** *For persons with severe mental illness, recovery has been defined as the process of living a satisfying life within the constraints of their mental illness. Schizophrenia is a severe complex mental health disorder characterized by an array of positive and negative symptoms, and the timing of the occurrence along with its chronic course, make it a disabling disorder for many patients and their families.* ***Method:*** *This small-scale exploratory study aims at measuring how a sample of 24 patients manages to cope with the diagnosis and evaluate their level of recovery from the illness. RAS-R was and data was analyzed according to the five dimensions of the scale: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, and autonomy.* ***Results****: Our sample generally obtained a mean value in the middle range of the scale showing that they manage quite successfully to accept the diagnosis and construct a positive image of the future. Even if we did not get significant differences according to gender, women showed better scores.* ***Conclusions:*** *The care model for persons with schizophrenia must be oriented toward a full recovery process. This means moving away from the assumption that care focuses on maintain or stabilizing the patients' mental health, to a more holistic approach that includes values such as hope, social inclusion, goal setting, and patient self-management.*

Key-words: *schizophrenia; recovery; patients.*

1. Introduction

Recovery in mental illness is a continuous process of building and living a satisfying and fulfilling life that is self-defined and irrespective of persisting symptoms and dysfunctions that may associated with a mental health diagnosis (Davidson et al., 2005). This contrasts with the traditional disease-oriented recovery that emphasizes symptom remission and functional improvement. A patient-oriented recovery focuses on the self-directed pursuit of personally meaningful life in the presence of a disability (Davidson et al., 2005; Silverstein and Bellack, 2008). In the last years, this view of recovery has become increasingly prominent in the field of mental health. Mental health recovery may be seen as living well with illness (Oades, Deane, and Crowe, 2017). Therefore, a series of guiding principles in the development and implementation of mental health services for people in recovery of mental illness have been proposed (Jacobson and Curtis, 2000).

The treatment model for patients with schizophrenia must also be oriented toward rehabilitation, integration, and not just on managing the symptoms. Left

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untreated, schizophrenia leads to severe emotional and behavioural problems. These further transfer into all aspects all social life (eg. legal, occupational, relational, financial areas). WHO (2019) acknowledges that schizophrenia is a chronic and severe mental disorder affecting 20 million people worldwide and it is associated with considerable disability and may affect educational and occupational performance. The symptoms generally start on adolescence and young adults and people with schizophrenia are 2-3 times more likely to die early than the general population. However, schizophrenia is treatable and treatment with medicines and psychosocial support is proved to be effective. Also, facilitation of assisted living, supported housing and supported employment are effective management strategies for people with schizophrenia.

Stigma, discrimination and violation of human rights of people with schizophrenia are common ad interfere with the success of the recovery program. Generally, portraying persons with schizophrenia as victims of the illness and as offenders, the media takes a more negative stance towards schizophrenia, spreading a distorted image of people with schizophrenia, which might contribute to stigma (Calo and Băban, 2013). Most studies consider that persons with schizophrenia are the most stigmatized category among those with a mental illness. Due to the chronicity and incomplete remission of the symptoms, a significant number of patients continue living in protected houses and/or hospitals and they do not reach the level of independent/autonomous adult who marry, have children and work (Mariș, 2013). The GAMIAN-Europe study (Brohan et al., 2010), carried in 14 countries and aiming at describing the level of self-stigma experienced by mental health service users with a diagnosis of schizophrenia or other psychotic disorders in Europe concluded that almost half (41.7%) reported moderate or high levels of self-stigma, 49.2% moderate or high stigma resistance, 49.7% moderate or high empowerment and 69.4% moderate or high perceived discrimination. These results confirm once more the need to change our attitudes as well and to support patients with mental illness in their recovery process. We believe that the high level of self-stigma is nothing more than a reflection of the stigma from the others. In other words, we may say that the level of stigma interferes with the recovery process because "low compliance or non-compliance in the early stages of the treatment and in the long term care is proportional to the intensity and type of stigma" (Fodoreanu, 2008: 32). Such persons will feel guilty for what is happening, will see himself/herself as unfit to carry certain tasks, will start to neglect himself/herself and will stop carrying about anything. When you stop carrying about yourself, why would you make an effort to recover, to follow your treatment plan? We believe that, in such cases, the stigma impacts the person more that the illness itself.

2. Method

2.1.Aim

The scientific problem of this paper is the high level of stigma associated to the persons with schizophrenia, which, in many cases impedes people to ask for professional help. Starting from this, we wanted to measure how the patients manage to cope to this diagnosis and evaluate their level of recovery from the illness.

2.2. Sample and data collection

Respondents were recruited from two Neuropsychiatric Recovery and Rehabilitation Centers from Suceava County. Questionnaires were filled in in physical format during November-December 2020. The total sample reached 24 persons aged 30-69, equally divided between males and females. The majority (75%) is not married. None of the respondents was employed at the date of data collection, 21 persons having a disability degree certificate and 2 an unemployment benefit.

2.3. Instrumentalization

Recovery Assessment Scale (RAS) is one of the most used tool in both English (see McNaught, et al., 2007; Hancock et al., 2011) and non-English speaking countries (see Chiba, Miyamoto, & Kawakami, 2010; Jorge-Monteiro & Ornelas, 2016; Mak, Chan, and Yau, 2016; Cavelti et al., 2017; Silva et al., 2017; Biringer & Tjoflåt, 2018; Guler & Gurkan, 2019; Boggian et al., 2020) for measuring recovery for people with mental illness (Salzer and Brusilovskiy, 2014; He, Fang, Huang, and Yu, 2021). For this study we used the 24-item revised version (RAS-R: Biringer and Tjoflåt, 2018) which yields five factors: (a) Personal confidence and hope (items 7, 8, 9, 10, 11, 12, 13, 14 and 21), (b) Willingness to ask for help (items 18, 19 and 20), (c) Goal and success orientation (items 1, 2, 3, 4 and 5), (d) Reliance on others (items 6, 22, 23 and 24), and (e) No domination by symptoms (items 15, 16 and 17). For each item, participants rated their agreement on a five-point Liker scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*) with higher scores indicating better outcomes in terms of recovery from mental illness.

Descriptive statistics of the RAS-R item responses, mean sub- and total scale are presented in Table 1.

Table 1. Descriptive of the RAS-R items and summary scales in the valid sample (n = 24)

Item	Mean	SD
Personal confidence and hope (α = .90)		
Fear doesn't stop me from living the way I want to	**2.87**	**1.22**
I can handle what happens in my life	**3.04**	**1.16**
I like myself	**3.79**	**1.06**
If people really knew me, they would like me	**3.75**	**.84**
I have an idea of who I want to become	**3.41**	**1.13**
Something good will eventually happen	**3.83**	**.96**
I'm hopeful about my future	**3.37**	**1.17**
I continue to have new interests	**3.37**	**1.13**
I can handle stress	**3.54**	**1.17**
Willingness to ask for help (α = .85)		
I know when to ask for help	**3.95**	**.69**
I am willing to ask for help	**3.83**	**.76**
I ask for help when I need it	**3.87**	**.74**
Goal and success orientation (α = .93)		
I have a desire to succeed	**3.91**	**.92**
I have my own plan for how to stay or become well	**3.58**	**1.24**

I have goals in life that I want to reach	**3.58**	**1.24**
I believe that I can meet my current personal goals	**3.54**	**1.25**
I have a purpose in life	**3.58**	**1.01**
Reliance on others (α = .81)		
Even when I don't care about myself, other people do	**3.56**	**1.03**
I have people I can count on	**3.56**	**1.03**
Even when I don't believe in myself, other people do	**3.47**	**.79**
It is important to have a variety of friends	**3.43**	**1.19**
No domination by symptoms (α = .77)		
Coping with my mental illness is no longer the main focus of my life	**3.33**	**1.09**
My symptoms interfere less and less with my life	**3.29**	**1.16**
My symptoms seem to be a problem for shorter periods of time each time they occur	**3.50**	**1.02**
RAS total (α = .77)	3.54	.77

Source: generated by the authors

2.4. Procedure

Giving the location of the study, approval for the study was obtained from the General Directorate of Social Assistance and Child Protection Suceava (DGASPC). Afterwards, the directors of the centers were contacted and the primary researcher explained the aim of the research. Explaining the selection criteria (respondents with a diagnosis of schizophrenia and capable to answer questions), the social worker then recommended and selected the potential respondents. Giving the pandemic situation where the direct access to the institution was not possible, questionnaires were filled in by the respondents with the help of social workers. Completed questionnaires were scanned and send by e-mail to the researcher. In order to assure the confidentiality, anonymity, and privacy of the responses, subjects were told that data will be available only to the research team and a contact number was provided for addressing future concerns. Answers were then checked for consistency and uploaded into SPSS software and used in analysis.

3. Results

Personal confidence and hope

With respect to the first dimension, "personal confidence and hope", the only significant difference is recorded for the item *If people really knew me, they would like me* [$t(22)= -2.72$, $p = .012$] with females displaying a more positive hope outcome. However, we notice that, compared to males, females in general display higher scores for all the items suggesting that they handle more easily their diagnosis, and they construct their future in a more positive manner.

Table 2. Sample statistics and p value for Personal confidence and hope

Item	***M***	***SD***	***t***	***df***	***p***
Fear doesn't stop me from living the way I want to			-1.93	22	.06
Male	2.41	1.16			
Female	3.33	1.15			

I can handle what happens in my life			.17	22	.86
Male	3.08	1.31			
Female	3.00	1.04			
I like myself			-1.37	22	.18
Male	3.50	1.16			
Female	4.08	.90			
If people really knew me, they would like me			-2.72	22	.01
Male	3.33	.88			
Female	4.16	.57			
I have an idea of who I want to become			-1.89	22	.07
Male	3.00	1.12			
Female	3.83	1.02			
Something good will eventually happen			-1.77	22	.09
Male	3.50	1.00			
Female	4.16	.83			
I'm hopeful about my future			-1.23	22	.23
Male	3.08	1.31			
Female	3.66	.98			
I continue to have new interests			-1.68	19.	.10
Male	3.00	1.27		33	
Female	3.75	.86			
I can handle stress			-.51	22	.61
Male	3.41	1.31			
Female	3.66	1.07			

Source: generated by the authors

Willingness to ask for help

We know that persons with schizophrenia have difficulties in adapting to new living conditions, are stigmatized, rejected and they need professional help to overcome the obstacles. Even if there were no significant difference noticed in our sample, we notice that females in general tend to acknowledge better their need of help and are more willing to ask for it.

Table 3. Sample statistics and p value for Willingness to ask for help

Item	***M***	***SD***	***t***	***df***	***p***
I know when to ask for help			-1.49	22	.14
Male	3.76	.59			
Female	4.18	.75			
I am willing to ask for help			.08	15.	.93
Male	3.84	.55		20	
Female	3.81	.98			
I ask for help when I need it			-.20	22	.84
Male	3.84	.55			
Female	3.90	.94			

Source: generated by the authors

Goal and success orientation

Women are also more confident and willing to do what it takes to have a functional life (see items *I have my own plan for how to stay or become well* and *I believe that I can meet my current personal goals).* Even if the t-test did not yield for significant differences, the mean values allow us to notice the better recovery process for women.

Table 4. Sample statistics and p value for Goal and success orientation

Item	*M*	*SD*	*t*	*df*	*p*
I have a desire to succeed			-.397	22	.69
Male	3.84	.68			
Female	4.00	1.18			
I have my own plan for how to stay or become well			-1.54	22	.13
Male	3.23	1.16			
Female	4.00	1.26			
I have goals in life that I want to reach			-.18	22	.85
Male	3.53	1.26			
Female	3.63	1.28			
I believe that I can meet my current personal goals			-1.39	20.93	.17
Male	3.23	1.42			
Female	3.90	.94			
I have a purpose in life			-1.04	22	.30
Male	3.38	1.12			
Female	3.81	.87			

Source: generated by the authors

Reliance on others

With respect to the fourth dimension, the only significant difference was recorded for the item *Even when I don't care about myself, other people do* [*t*(22)= -3.01, p = .007] suggesting that females have better connection with the outer group. In general thou, we also notice that the mean recorded for females in slightly higher than for males, suggesting that the support group is higher and more accessible to them when needed. We know that support from friends and family is very important in the recovery process and in sustaining the positive outcomes during treatment so we consider that this dimension is an important entry point for targeted interventions. This higher value for reliance on others correlates to the willingness to ask for help and with personal confidence and hope.

Table 5. Sample statistics and p value for Reliance on others

Item	*M*	*SD*	*t*	*df*	*p*
Even when I don't care about myself, other people do			-3.01	21	.007
Male	3.07	1.03			
Female	4.20	.63			
I have people I can count on			.18	22	.85

Male	3.53	1.12			
Female	3.45	1.03			
Even when I don't believe in myself, other people do			-1.84	21.07	.06
Male	3.23	.72			
Female	3.81	.75			
It is important to have a variety of friends			-.67	20.93	.50
Male	3.30	1.10			
Female	3.63	1.28			

Source: generated by the authors

No domination by symptoms

With no significant differences for any of the items, however we noticed again the higher mean is recorded for females, suggesting that they are slightly better managing the symptoms and in controlling their life in spite of the diagnosis.

Table 6. Sample statistics and p value for No domination by symptoms

Item	***M***	***SD***	***t***	***df***	***p***
Coping with my mental illness is no longer the main focus of my life			-1.26	22	.21
Male	3.07	1.11			
Female	3.63	1.02			
My symptoms interfere less and less with my life			-1.81	21.51	.08
Male	2.92	1.25			
Female	3.72	.90			
My symptoms seem to be a problem for shorter periods of time each time they occur			-1.03	22	.32
Male	3.30	1.10			
Female	3.72	.90			

Source: generated by the authors

Running a t-test for independent samples for all the five dimensions of RAS we concluded that there are no significant differences between males and females for Personal confidence and hope [$t(22)= -1.81$, $p=0.08$], Willingness to ask for help [$t(22)= -0.62$, $p=0.54$], Goal and success orientation [$t(22)= -1.17$, $p=0.25$], Reliance on others [$t(21)= -1.68$, $p=0.11$], and Autonomy [$t(22)= -1.991$, $p=0.06$].

4. Conclusions and Discussion

The aim of the current research was to evaluate the degree of acceptance of the illness and diagnosis of schizophrenia. By 'acceptance' we did not mean a deterministic and fatalistic view of patients in facing a situation that limits their possibilities, blocks their future initiatives and hope regarding their future, but their level of adaptation to the illness allowing them to live functionally with the diagnosis. The instrument we

used focuses on recovery as a proxy measure for adaptation. Recovery is seen both as a result and as a process (He et al., 2021).

In a study carried on a Romanian sample, compared to men, women with schizophrenia reported a lower degree of disability and a better quality of life. This difference may be due to the later onset of the illness in female patients and their better compliance to the treatment (Roşca et al., 2018). In testing this hypothesis we measured for the differences according to gender regarding personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others, and autonomy. Even if our results did not show significant differences, women in general obtained higher mean scores for all the dimensions indicating that our results are similar to previous studies. In general, women with a schizophrenia diagnosis display a positive image about their future life and they are also more inclined to ask for help when needed and act more independently. They manage to live with the illness and not against it.

However, there are a series of limitation to consider when looking at these results:

- small sample size and sampling procedure (convenience) employed did not allow us to generalize the findings to the population with a schizophrenia diagnosis;
- research instrument chosen (questionnaires) did not allow for a fully understanding of their experience in living with the illness;
- research procedure constraints that did not allow for direct face-to-face interaction with the respondents limited our control in filling in the measurements.

But, in conclusion, our exploratory objectives were fully met. Concluding that that for the 24 respondents included in the study, patients displayed positive attitudes toward the illness, emphasis the need to look at these persons in a more functional manner and to continue offering support services. These persons proved that they manage to live with the illness.

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