P-ISSN: 2617-9806
E-ISSN: 2617-9814

Impact Factor: RJIF 5.2
www.nursingjournal.net

International Journal of Advance Research in Nursing

Volume 6; Issue 2; Jul-Dec 2023; Page No. 01-05

Received: 23-03-2023
Accepted: 25-04-2023

Indexed Journal
Peer Reviewed Journal

Perceptions of medication adherence and non-adherence among patients with schizophrenia: A qualitative study from India

Helen Sujatha Charles[1], Dr. Manoranjitham Sathiyaseelan[2], Dr. Ciby Jose[3] and Rajeswari Siva[4]

[1] Retired Professor, Department of Psychiatric Nursing, College of Nursing, Christian Medical College, Vellore, Tamil Nadu, India

[2] Professor and HOD, Department of Psychiatric Nursing, College of Nursing, Christian Medical College, Vellore, Tamil Nadu, India

[3] Principal, Venkateswara Nursing College, Thalambur, Chennai, Tamil Nadu, India

[4]Professor, Department Community Health Nursing, College of Nursing, Christian Medical College, Vellore, Tamil Nadu, India

DOI: https://doi.org/10.33545/nursing.2023.v6.i2.A.332

Abstract

Background: Antipsychotic non-adherence is associated with an increased risk of relapse. Discontinuation of antipsychotic medication continues to be a common problem in the treatment of patients with schizophrenia. It is important to develop strategies to improve medication adherence. Little qualitative research has been conducted to understand the consumer perspective. Therefore, the scientific literature lacks the voice of those who have been prescribed these drugs.
Aim of this study was to explore the Perceptions of primary caregivers and patients with schizophrenia about medication adherence and non-adherence.
Methods: Focus group discussions were held with 12 patients with schizophrenia and 12 primary caregivers of patients with schizophrenia. A semi-structured interview guide was used to understand the various aspects and issues related to medication adherence and non-adherence.
Results: Based on the experiences and descriptions of primary caregivers and patients, a clinical practice model was created to improve adherence. The target interventions expected from the participants are mainly education and encouragement from family, friends and society. Most participants stated that both patients and their primary caregivers should understand the importance of medications, and family members should share the positive benefits of medications with patients. Education should be provided to manage adverse drug reactions that may lead to medication adherence.
Conclusion: These findings suggest that family, health care providers, and society often need to encourage patients to improve medication adherence. Patients must trust the treatment and understand the benefits of the medication in terms of good adherence.

Keywords: Family, schizophrenia, schizophrenia

Introduction

Schizophrenia is one of the 10 most common diseases that increase the global burden of disease and have high rates of relapse. Global recurrence rates range from 50% to 92% and are similar in developed and developing countries. Relapse is associated with several factors, the most common of which is poor adherence. Medication non-adherence is very common in patients with schizophrenia [1]. In schizophrenia, the non-adherence rate is 50% and varies widely from 4% to 72% [2]. Adherence to medication is necessary but difficult in the field of psychiatry [3]. A meta-analysis of 35 studies looking at a pooled assessment of medication non-adherence found a 56% adherence rate for schizophrenia, major depression (50%) and bipolar disorder (44%) [4]. Antipsychotic drugs effectively prevent the recurrence of the disease if they are used regularly [5].

Schizophrenia is a lifelong disease with the lowest treatment compliance. Quantitative research isolates variables as part of medication adherence that cannot be understood from the perspective of improving medication adherence as a whole. Qualitative research typically involves in-depth interviews, focus group discussions, or observations, which are used to gather detailed and contextual information. It is often used to investigate complex phenomena or to obtain information about people's experiences and perspectives on a particular topic. However, quality research on non-adherence to antipsychotic medication is lacking.

One qualitative study of the views of patients, carers and professionals on adherence highlighted a misunderstanding of what determines adherence, highlighting the need to develop mutual understanding and a strong therapeutic alliance [6]. Involving caregivers in the treatment of patients

with schizophrenia is one strategy to increase medication adherence. Nurses have a positive influence and can help patients change their attitudes towards illness and improve their attitudes to increase compliance.

Aim

Of this qualitative study was to explore primary caregivers' and patients' perceptions related to medication adherence and nonadherence in Schizophrenia. Reasons for nonadherence to antipsychotic medication and learning about the need for adherence from a self-perspective.

Methods

This study was based on qualitative research methodology and used focus group discussions to gather information on strategies to improve medication adherence in schizophrenia. Ethics approval was obtained from the local research ethics committee (IRB No. 10135). All participants gave signed informed consent to understand the study and audio recording of the interviews.

Sample

Participants were primary caregivers (spouses/siblings/children) and patients with schizophrenia attending a tertiary psychiatric facility at Christian Medical College, Vellore, India. Patients had to be clinically stable and have more than six months of antipsychotic medication. Purposive sampling technique was used in selecting participants.

Data Collection

Four focus group discussions took place. Two focus group discussions were held with patients and two other focus group discussions with primary caregivers of people with schizophrenia. The focus group guide was developed based on the results of previous studies. The main topics of the focus group discussions were:

- Causal explanatory models of illness
- Treatment explanatory models of illness
- Reasons for non-adherence to medication
- Consequences of non-adherence to medication
- Advantages of medication adherence
- Ways to improve medication adherence

Each focus group discussion was recorded with the written consent of each participant and transcribed verbatim. Sociodemographic characteristics were collected from the participants. 6 members were selected by purposive sampling method according to gender. Four focus group discussions took place. The discussion took place in a separate room where adequate seating, lighting, ventilation and privacy were ensured. The discussion was conducted by the researcher in Tamil and audio recorded by the co-researcher. A semi-structured guide was used for data collection. The interview lasted about 30-45 minutes. The interview started with a preliminary remark by the researcher, during which all the instructions were given to the participants. If the researcher felt that no new answers were received from the participants, the interview ended with the researcher's notes.

Data analysis

Transcription and translation

The recorded conversations were transcribed verbatim (in Tamil). The transcripts were translated into English. The back translation was done by a third person and the congruency between the transcript and the translated version was verified.

Coding and classification

Coding was done manually by three independent researchers, and consensus was reached between all three coders. The most frequently occurring codes were grouped into categories (sub-themes) and a relationship was created between the categories.

Emergence of theme and model

These codes and categories have evolved into a clinical practice model to improve medication adherence.

Results

Demographic characteristics: Twelve primary care providers and 12 patients participated in four FGDs. 12 of them were men and 12 women, age range 24-50 years. The primary caregivers were mostly parents, spouses and children. All of these participants had at least 2 years of experience caring people with schizophrenia.

Causes of mental illness

Most primary care providers and patients indicated that increased pressure, tension and thinking are contributing factors to mental health problems. One of the primary caregivers mentioned, "Often my wife gets stressed and there is pressure and overthinking in the brain. Because of them, she got mental illness." Few patients seem to believe in mythological beliefs, one of the patients mentioned, "I have God in me, that's why I get this illness." Another patient mentioned, "God is speaking with me for the last 3-4 years, due to increase in spirituality developed this illness. The themes that emerged were increased tension, pressure in the mind, stress, crisis and loss.

Treatment of mental illness

Most participants said that medication and counselling are treatments for mental illness. Few participants mentioned that both medication and counselling should be provided to treat patients with mental health problems. Participants mentioned that patients need support, love and care from their family members to receive treatment and medication. One participant from the primary care giver group mentioned, "Family members should be supportive and not leave thinking they are fine. They should not be left alone in the house."

Reasons for refusing medication

The most common reasons given by study participants for refusing medication are that the patient feels healthy, normal, well, and lacks information about mental illness. The second most common reason for patients is drugs that have caused side effects. As a result, patients had to stop taking the drug. Few patients stopped taking the drug

because they were afraid of having to use the drug for life. One patient from the group described it as follows: "Constantly taking medication makes me afraid that I will have to take medication for the rest of my life and not be able to enjoy it with my wife". Perceived stigma and experienced stigma were cited as strong barriers to patients not taking medication. One of the participants shared her experience of stigma, "others started saying that she is on medication, that she is loose. I thought, let me be normal and brave and I stopped taking the medication". Some participants stopped taking the drug when they found no improvement.

Consequences of not using medicines

The majority of participants in both the primary caregivers and patient groups indicated that if patients do not take medication, they will return to an earlier stage of the disease, continue to have problems and become sicker, and the disease may worsen. One participant from the primary caregiver group mentioned, "They go back to the previous stage of the disease with all the symptoms. They start harming themselves and others. If they stop taking the medicine, the disease can get worse." Some participants said that patients' symptoms get worse and they can be aggressive towards themselves and others. One participant in the patient group mentioned: "They still have their problems, unable to work and communicate with people, argue and be upset because they can't be like others." One participant in the patient group said that after all the symptoms appear, patients realize that they need medicine for their illness.

Advantages of using the drug

The majority of participants in both groups stated that the benefit of regular medication is that patients get better, will become normal and recover from their disease. Patients are in a relaxed state and control their behaviour. One participant from the primary caregiver group said: "They can relax and control themselves. They sleep well for 6-7 hours, sleep relaxes their brain and body, which makes them fresh the next day." In addition, most of the participants said that taking medication helps to reduce problems and they are able to work and care well of their families. One of the participants mentioned, "They are able to work well and take care of the family". However, some of them said they still experienced side effects such as weight gain, drowsiness and inability to work.

Measures to improve medication use

Most participants in both groups said that if we make patients simply understand the need for medication, they will take their medication regularly. One of the participants mentioned, "Let them know that taking their medicine will keep their disease under control and they will be fine." Most participants said that if patients are unresponsive and uncooperative, medicines can be given by mixing with fluids and food. The participants also recognized that family members should initially understand the patient and give medicine until the patient is able to take it on their own, in addition, family members should support, encourage and motivate the patient to discuss the positive aspects of the medicines "The family should encourage them to take the medicine." Another important measure to improve patient compliance, participants reported the need to explain and educate different measures to manage adverse drug reactions. One of the participants mentioned, "If they know how to manage the side effects, they will take the medicine without stopping".

Some participants said that sharing real-life experiences of recovering from an illness after taking medication is one way to increase medication adherence. Show them patients who got better after taking the drug. Some participants indicated that doctors should mainly advise family members to understand patients and to be helpful and supportive when taking medication. One participant in the patient group said: "Family members should understand our problems and cooperate. Family members should not say that we are crazy, they should explain the illness and the need for medicine to family members".

Discussion

This qualitative study examined the reasons for antipsychotic medication adherence and non-adherence in primary caregivers and people with schizophrenia.

Increased tension, pressure in the mind, stress and acute crisis were the causes of mental illness identified in this study. It also revealed that the participants believed in myths about the origin of mental illness. Regarding treatment for mental illness, most participants said medication and counselling. This shows that they believe in psychological treatment. Regarding the reasons for refusing medication, most participants indicated that lack of knowledge and understanding about the nature of the disease and the medication was an important factor. Hanlon, Tesfaye, Wondimaegn, and Shibre (2010) reported a similar finding that poor insight was one of the reasons for low medication adherence [7]. It was also mentioned that considering the apparent absence of symptoms as treatment led to medication discontinuation. Or, on the contrary, they expected too much from the treatment, and when there was no "improvement" they stopped taking the medicine.

The majority of participants in both the primary caregivers and patient groups indicated that if patients do not take medication, they will return to an earlier stage of the disease, continue to have problems and become sicker, and the disease may worsen. Some participants said that patients' symptoms worsened and they could be aggressive towards themselves and others. One participant in the patient group said that after all the symptoms appear, patients realize that they need medication for their illness.

Most participants considered the many benefits of medication adherence to patients and their families. In most cases, patients' problems are resolved and they can return to their previous condition, take care of their families and work well. This indicates that participants are more aware of the benefits of medication adherence. Various options for augmenting medication adherence were discussed, participants wanted the mental health team to educate on the benefits of medication. Participants wanted this to be explained simply so that patients would understand that if patients understood, medication adherence would certainly increase. Adverse drug reactions were often cited as an important factor leading to non-adherence among these participants. Hanlon, Tesfaye, Wondimaegn and Shibre

(2010) reported a similar observation of patients discontinuing medication due to unpleasant side effects [7]. Both patients and primary caregivers need information on measures to manage side effects. Another important factor influencing medication adherence was the role of the family in patient care. In the absence of community-based mental health care, patients relied on family support to take medication. Because of the negative and cognitive symptoms of schizophrenia, patients may be too unwell, unintelligible, or unable to remember to take their medication. Family members also play an important role in ensuring that a sick relative takes their medication through reminders and encouragement.

In addition to motivation, family members should regularly encourage and share the positive effects of medication, which in turn improves compliance. Most participants in this study suggested that medications for uncooperative patients could be mixed with fluids and food. Hanlon, Tesfaye, Wondimaegn and Shibre (2010) [8] conducted a study on "Ethical and Professional Challenges in Mental Health Care in Low- and Middle-Income Countries" and found that some family members went so far as to mix drugs with drink (tea, milk) this type of covert drug administration is often used in patients living in low and middle-income countries.

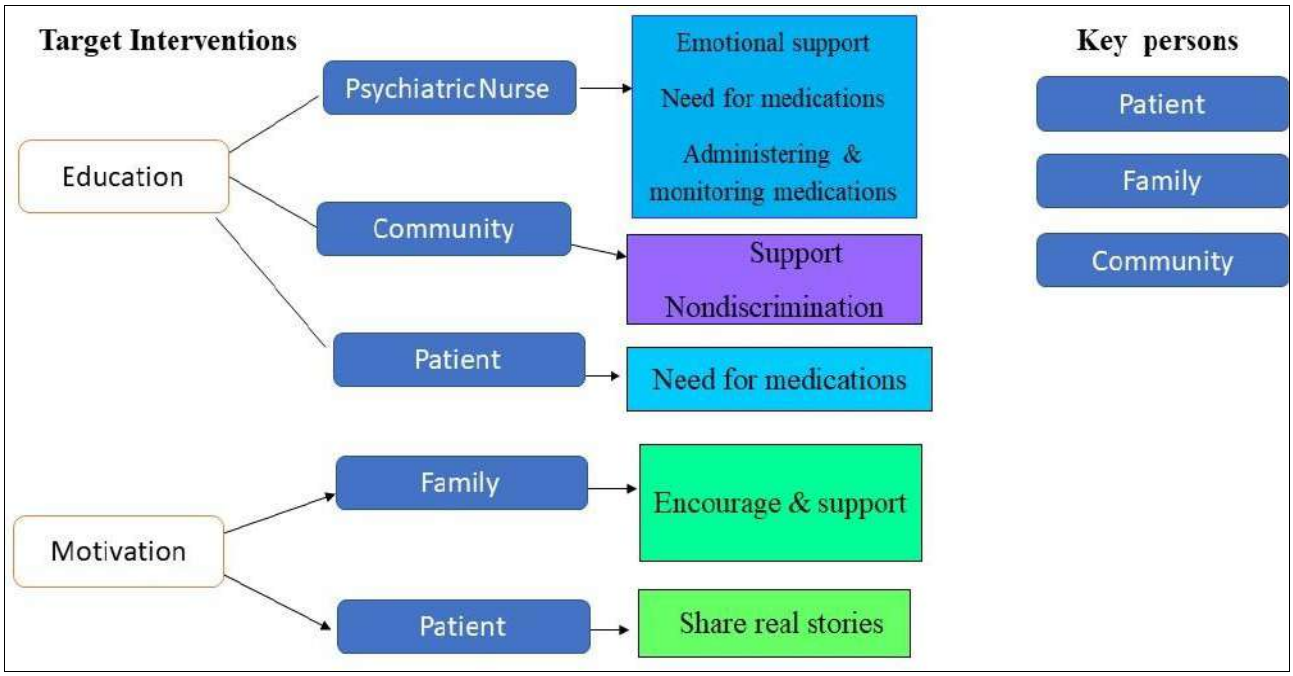

Fig 1: Clinical Practice Model of Enhanced Medication Adherence

Conclusion

This Qualitative study conducted on medication adherence and non-adherence have provided useful information about the various factors involved in understanding their disease, the reasons for poor adherence, and strategies to improve adherence from the perspective of the consumer and their family. In the clinical setting, the voice of the patient and primary caregivers must be considered when directing their care. Healthcare providers, particularly nurses, could use this information to provide psychoeducation and motivation to improve patient medication adherence.

Conflict of Interest

Not available

Financial Support

Not available

References

1. Anna Hegedüs, Bernd Kozel. Does adherence therapy improve medication adherence among patients with schizophrenia? A systematic review international journal of mental health nursing. 2014 Dec;23(6):490-497.
2. Singh P, Karmacharya S, Khadka S. Severity of Relapse and Medication Adherence in Patient of Schizophrenia: A Study from Nepal. Journal of Psychiatrists' Association of Nepal. 2019;8(2):54-58.
3. Lauriello J, Perkins DO. Enhancing the treatment of patients with schizophrenia through continuous care. J Clin. Psychiatry. 2019;80:al18010ah2c. [Google Scholar] [Cross Ref] [PubMed]
4. Semahegn A, Torpey K, Manu A, Assefa N, Tesfaye G, Ankomah A. Psychotropic medication non-adherence and its associated factors among patients with major psychiatric disorders: A systematic review and meta-analysis. Syst. Rev. 2020;9:17. [Google Scholar] [Cross Ref] [Pub Med][Green Version]
5. Tham XC, Xie H, Chng CML, Seah XY, Lopez V, Klainin-Yobas P. Exploring predictors of medication adherence among inpatients with schizophrenia in Singapore's mental health settings: A non-experimental study. Arch. Psychiatr. Nurs. 2018;32:536-548. [Google Scholar] [Cross Ref]
6. Kikkert MJ, Schene AH, Koeter MW, Robson D, Born A, Helm H. Medication adherence in schizophrenia: exploring patients', carers' and professionals' views. Schizophr Bull. 2006 Oct;32(4):786-94.

DOI:10.1093/schbul/sbl011. Epub 2006 Aug 3. PMID: 16887889; PMCID: PMC2632275.
7. Lucinda Clifford, Shona Crabb, Deborah Turnbull, Lisa Hahn, Cherrie Galletly. A qualitative study of medication adherence amongst people with schizophrenia Archives of Psychiatric Nursing. 2020 Aug;34(4):194-199.
8. Hanlon C, Tesfaye M, Wondimagegn D, Shibre T. Ethical and professional challenges in mental health care in low- and middle-income countries. Int. Rev Psychiatry. 2010;22(3):245-51. DOI:10.3109/09540261.2010.482557. PMID: 20528653

How to Cite This Article
Charles HS, Sathiyaseelan M, Jose C, Siva R. Perceptions of medication adherence and non-adherence among patients with schizophrenia: A qualitative study from India. International Journal of Advance Research in Nursing. 2023;6(1):268-272