Reasons for non-compliance to treatment among patients with psychiatric illness: A qualitative study

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Abstract

Aim: To understand the reasons for non-compliance to treatment among patients suffering from psychiatric illnesses in Mmametlhake health district, South Africa.

Setting: Mmametlhake health district, Mpumalanga province, South Africa.

Methods: A descriptive, qualitative study was done using a free attitude interview technique. Each respondent's interview was paired with that of his/ her family member (care giver) and later integrated into a single model to obtain integrated themes.

Results: Side effects of medications were the most common reason for non-compliance to treatment. Other reasons were respondents' different belief systems, poor insight about their illness, ineffectivity of some medication, dislike for injections, lack of continuity of care and family support, non-involvement of patients in their own management. Social stigma, objection by a particular religious group to treatment and cancellation of disability grant were also linked to some patients' non-compliance to treatment.

Conclusions: Through better understanding of the reasons mentioned in this study and increased co-operation between primary care clinicians, patients and their caregivers, non-compliance to treatment among patients with psychiatric illnesses can be significantly minimized. Further studies are necessary to confirm these findings and evaluate intervention strategies.

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INTRODUCTION

About 20-25% of all general practice attendees suffer from significant psychiatric illnesses.[1] Non-compliance to treatment has always been one of the biggest challenges to GPs world wide.[2] Apart from treatment failures, non-compliance to treatment is one of the main causes of relapse and re-hospitalisation world wide.[3] Non-compliance to treatment is a complex phenomena that is associated with various factors related to the illness, medications and health care delivery system.[4] Existing literature suggest that many psychiatric patients do not believe in the biological basis of their illness.[5,6,7] Hence lack of understanding and lack of confidence in "Western" approach is a major contributor for non-compliance in such patients.[8] Several investigators report that lack of insight into the illness and poor understanding of the chronic nature of psychiatric conditions contribute greatly to non-compliance.[9,10,11,12] However, other studies suggest that poor insight may not fully explain this behaviour.[13,14] The phenomena is also found to be associated with complexity of medication regimens.[15,16] Studies on non-compliance to treatment among psychiatric patients are few and mainly done in urban settings or specialized care institutions. This study was conducted in a rural setting with an appreciable number of non-compliant patients and where mental health service is rendered by general practitioners.[17] The focus of the study was on the subjective aspects of the patients' reasoning and perspective of their care giving relatives.

METHODS

The aim of this study was to understand the reasons for non-compliance to treatment among psychiatric patients in Mmametlhake health district, South Africa. Non-compliant patients were identified using clinical records. Six non-compliant patients from five families (two of the respondents were brothers) were purposefully selected, ensuring wide variations in clinical diagnosis, medication regimen, gender, and marital status.[18] A descriptive, qualitative method was used as the choice to focus on exploring and understanding the experiences and behaviours of the non-compliant patients.[19] All interviews were conducted in Tswana, transcribed verbatim and translated into English. The information from the research diary and field notes was incorporated into the data. The respondents to verify the correctness of the data did "member checks". Colour coding and "cut and paste" method were used to identify themes from each interview.[20] The analysis of each patient's interview and that of his/ her care giver were integrated into a single model and, similar themes from segmented data were grouped together to form various categories. We used 'grounded theory' to relate abstract concepts to propose a theory as an explanation of a specific phenomenon and to identify analytical categories as they emerged from the data.

RESULTS

As various themes emerged from the data, it was found that multiple causal factors were associated with each patient's non-compliance. The integrated themes are presented as follows:

Patients' different belief systems

Different belief systems were found to be associated with medication non-compliance of some patients. They believed *"witchcraft"* as the cause of their illness and rather took "healing herbs at the church" as its remedy. Another patient identified *"stress"* as the core of his illness and thought that medication could not relieve his symptoms unless the stress was resolved.

Poor insight and denial

Majority of the patients had poor insight about their illness. One of them said he was *"on pills for a long time and left them as he thought that he was "cured"*. Another one did not take her medication, as she believed *"every thing was well"*. More over she perceived that the community had wrongly identified her as a psychiatric patient. She said: *"They say this person is mad, while you are a prophet"*. Some patients were in a state of denial. They did not see any reason to continue medication when the *"illness is no longer there"*. One patient believed that he *"did not have a brain problem"* and subsequently stopped the medication.

Side effects of medications

Almost all patients mentioned side effects of various medications as a deterrent to compliance and the care-giving relatives objectively confirmed this. In some cases, the patients preferred the experience of symptoms related to the disease rather than the medication side effects. The respondents used expressions such as *"sleepy"*, *"weak"*, *"powerless"*, *"dizzy"*, *"no energy"* to highlight the side effects. Some complained that *"the pills made me sleepy"*, *"My tongue is always out of my mouth with drops of saliva coming out"* and *"I can not even speak"*. These observations occurred irrespective of what medications they took. It was found out that none of these patients were informed about side effects, possible remedies and coping strategies before commencement of drug therapy. Although some of them were put on anti-parkinsonian drugs, the effectivity of these drugs was never evaluated.

Ineffectivity of medications

Some patients and their relatives informed that the medications were ineffective. One of them mentioned: *"The treatment I was taking did nothing for me"*. The mother of another patient said: *"They (the nurses) gave medication, but it failed"*. It appeared plausible that some found the rationale for continuation of medication for a long time hard to understand, especially if its main function was prophylactic.

Fear and dislike of injection

One patient expressed his fear and dislike of injection he was receiving as his reason for non-compliance. During the interview he mentioned his disgust six times: *"The injection made me sick"*. His relative confirmed: *"The injection caused complications"*. It appeared that this patient developed extra pyramidal symptoms after receiving fluphenazine depot injection. Despite his concerns, he was repeatedly injected with the same drug.

Lack of family support

Lack of family support was identified by half of the patients for their non-compliance. They mentioned *"misunderstanding"* within the family as an issue. One of them complained *"They (the family members) chased me away"*. Another patient directly attributed his default of treatment to family discord: *"I skipped four months because we had a difference of opinion at home"*.

Improper persuasion strategy

To ensure compliance, one family coerced the patient into taking her medication. This strategy of forcing the patient rather than understanding and promoting insight made the patient more rebellious. The patient's mother acknowledged: *"We brought her to Lefisoane (clinic) forcefully; she refused, and we were fighting"*.

Lack of continuity of care

Lack of continuity of care was identified as a deterrent to compliance to treatment in some patients. One patient angrily said: *"Every time I came for treatment, they (the clinic nurses) said my file was missing"*. He was very disappointed that at each occasion he had to tell his story over and over again until he promised himself *"I will never come back again"*. As there was no doctor specifically allocated to these patients, there was no continuity of care. One of them claimed he *"never saw"* the same doctor twice.

Lack of ongoing assessment

The interviews of half of the patients revealed lack of ongoing assessment. Two patients appeared to have their symptoms controlled and they believed their symptoms had resolved. However, they were not reassessed on the basis of

their changing context or on the basis of changing magnitude of their illness to redefine "compliance" in them. On the other hand, another patient's symptoms were not controlled despite compliance to treatment and but no assessment was done for possible dose adjustment or modification of drug regimen.

Non-involvement of patients and families in management plans

In most cases the patients and their families expressed frustrations in the non-involvement of their clinical management. The nature of the illness and pattern of therapy were not explained to them as one patient said: *"I did not know what was what"*. Another patient, who was initially on oral medication, had a depot injection added without any explanation. He expressed his surprise: *"I went (to the clinic) to collect the pills and they (nurses) injected me as well"*. The care-giving relatives accompanied patients to the health facility but were barred from entering the consulting rooms with them.

Cancellation of disability grants

The association between non-compliance to treatment and cancellation of disability grants featured prominently in two patients. The mother of one patient positively identified her son's non-compliance with cancellation of his disability grant. The patient's disability grant was cancelled when he became *"symptom free"* on treatment. The family depended on his grant and when it was stopped, this created financial strain within the family. The mother claimed: *"That is when he totally left them (the medication)"*. The patient reflected *"I got pension for three years, when I took treatment my pension was cancelled"*.

The other patient's application for disability grant was rejected when the welfare officer identified that he came alone to lodge a renewal of his application, implying that he was no longer sick. He regretted that *"they (welfare officials) tore them (the application forms) saying I am okay and I should go and look for work"*. The lack of understanding by these officials made him realise that he could not receive a disability grant if he remained symptom free.

Social stigma

Adverse social stigma towards psychiatric patients contributed to non-compliance to treatment in some of them. They were embarrassed by their *"mentally ill"* identity and avoided going to the clinics on a specific day assigned for reviewing psychiatric patients. One relative said *"They go to the clinic on the day that they were not suppose to go"*. Eventually they missed their scheduled appointments for review.

Religious sect's objection to medical treatment

One of the religious sects featured prominently in the interview of one patient. She claimed that the sect wanted her to take *"healing herbs and to pray instead of taking any medication*. She told us *"One priest stood there and said, people should not take their medication"*. The mother of this patient agreed with this claim and said, *"She was not allowed to take medication"*.

Autonomy and ego

It was discovered that the desire for independence and self-control played a pivotal role in most of the patients' non-compliant behaviour. They were not involved in their own management. The approach was often confrontational and coercive. It ultimately made them rebellious and resisted attempts to control their lives by drugs, as their relatives expressed frustration as follows: *"When a person is grown up, you cannot control him"*.

"Lastly we fought". "At the end I was unable to force her". "He used his manly power, so I could not do any thing more".

DISCUSSION

The choice of qualitative method in conducting the study was found to be logical as the research was aimed at understanding the patterns of behaviour in a group of people and as it was focused on a holistic insight about a phenomenon grounded in its own context.[21] The sample represented a cross section of the study population who were able to provide relevant information as the key informants. The variation in gender, diagnosis and in treatment regimens ensured that despite relatively 'small size', the sample was a fair and adequate reflection of the study population and thus maximized the transferability of the study.[22] The use of exploratory question in the participant's first language (Tswana), audio taping of interviews, field notes and research diary enhanced reliability and validity of the study. The idea of conducting free attitude interviews was to allow unstructured responses from the participants, as the question was open ended.[23]

We derived the results of this study from the data through its interpretation and conceptualisation. Some of these results are consistent with those in existing literature, and interestingly some other opened windows for new dimensions of thinking. However, in all cases the reasons were linked to multiple factors rather than one specific cause. Side effects of different medications (e.g. extra pyramidal symptoms, dizziness, drowsiness, weakness etc.) were mentioned by most of the patients for non-compliance. At the same time about half of the patients attributed their non-compliance to alleged ineffectivity of medications.

It was found out that the patients (and their families) were not generally involved in managing their illness. The paternalistic approach by the health professionals, coercion by family members and lack of continuity of care were also highlighted. The health workers did not provide enough information to the patients and their families about the illness and about the role of medication. They also failed to address the concerns of the patients and their relatives (e.g. concerns about side effects), which hindered medication compliance. Patients' cultural values and belief systems were also associated with non-compliance to treatment and some patients expressed their faith in the "church" and "spiritual healing". Others were in denial and did not believe that they were "mentally ill". They also demonstrated poor insight about their illness. Inadequate family support and lack of compassion by the family were

also linked to the problem. These circumstances prevented a conducive environment for medication supervision by the family that is essential for promoting compliance.[24] The coercive strategies used by some families failed to ensure compliance to treatment.

Social stigma and fear of labelling attributed to non-compliance in some patients. They were not willing to identify themselves as psychiatric patients. So they avoided going to the clinics on the specific review dates in an attempt to escape labelling. It is important to note that this particular behaviour was not identified in the previously conducted studies we went through. There were few other interesting themes emerged from this study. One patient mentioned the objection of her religious sect to the medical treatment and her mother confirmed the fact. Surprisingly, another patient who belonged to the same sect did not mention this objection. For better understanding this needs further inquiry about this sect for objective confirmation of its position on the management of its members suffering from psychiatric illness. From the interviews of two patients, the cancellation of their disability grants resulted in their non-compliance to treatment. These patients were denied disability grants apparently because they were symptom free on treatment. The patients and the families realized that the grants were declined as the patients took their treatment and were in stable conditions. It created an enormous impact on the families, as they were dependent on the grants. The mother of one patient confirmed that he "totally left" his medication after cancellation of disability grant. The behaviour of these patients represented "sick role deviation" by them. It was not clear whether these patients' non-compliance was their own initiative or influenced by the families' attempt to portray them as "uncontrolled" in order to receive disability grant. It was however obvious that the families directly or indirectly benefited from the patients' non-compliance through receiving of disability grant. This finding highlights the issue of 'secondary gain' as reflected in various studies.[3,25,26] Although the latter mentioned the possibilities of secondary gain, no explicit account of the nature of gain emerged as it did in this study.

This study adds a new dimension to understanding non-compliance to treatment among patients with psychiatric illness from family practice perspective by its methodology and design that were pragmatically justifiable when compared to the previous quantitative studies. This study supports findings of some previously conducted research[9,10] and contradicted one study.[16] New areas of exploration has also been suggested in terms of examining the relationships between medication non-compliance and disability grants, and religious groups' views on anti psychotic medication.

CONCLUSIONS

We believe that the management of patients with psychiatric illnesses can be improved by addressing the reasons of non-compliance as highlighted in this study. However, more qualitative research needs to be undertaken in various contexts similar to and different from our study. It will provide an understanding about the socio-demographic variables that affect medication compliance.❐

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