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Patients' Subjective Experiences of Psychotropic Drugs: Can These Help Gaining New Insights into Pharmacotherapy ?

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ABSTRACT

Currently, there is a promising renewal of interest in patients' personal experiences and interpretations of illness and treatment in psychiatric research. The main question of the present study is: If we learn to listen carefully to what patients experience when take psychotherapeutic drugs, could this have the potential to enrich and expand our knowledge of clinical psychopharmacology? The presented clinical material may help further illumination of such a question.

INTRODUCTION

Psychopharmacology is a young discipline, and is "still a blend of art and emerging science" (Shader, 1987). Most of the large number of controlled trials of new drugs" contribute almost nothing to clinical understanding and wisdom", and "the results of such trials depend more on arbitrary rating scales than on clinical perceptiveness" (Dally and Connolly, 1981).

Although the effects of psychotropic drugs can be studied at many different levels, there have almost been no systematic studies of the patients' self-reports of their subjective experiences of these effects. The great importance of the patients' personal experiences and interpretations of illness and treatment should be appreciated. Recently, there is a promising renewal of interest in this kind of data in psychiatric research. The challenge is how to discover and develop methods of inquiry and observation that "preserve subjectivity" and "protect rather than reduce experiential data" (Estroff and Strauss, 1989).

Hogan *et al.* (1983) said that " a reliable measurement of patients' self-reports of the medicated experience may prove to be useful as a predictor of drug compliance, and possibly also in other areas of psychopharmacology." Also, Van Putten *et al.* (1985) suggested that "the most practical predictors of outcome appear to be early clinical change and the subjective response after the first or the first several dose(s)". These measures , as stated by the authors, need substantiation.

The aim of this introductory work is to give a few examples of the patients' self-descriptions of their subjective experiences of the psychotropic medications they are receiving. The uderlying premise is that appropriate attention to and systematic recording of the statements made by the psychiatric patients themselves about the medications they are receiving may further our understanding of these medications.

SUBJECTS AND METHOD

For the purpose of the present study, some questions had been formulated with the aim of inquiring about certain aspects of the subjective experiences of the patient who was taking some sort or another of the well known psychotropic drugs. These questions were largely derived from the spontaneous statements made by some patients during psychotherapy sessions which describe, in detail, their experiences with the drugs.

A total number of 35 patients, with various psychiatric diagnoses as well as

varied durations of illness, was interviewed. Most patients were at the outpatient level and a small number was selected from the inpatients in Dar El-Mokattam for Mental Health. Both males and females were represented and a wide range of age was included. The patients, as a whole, were on various types of psychoactive drugs so that most of the broad categories were present in the sample. The current duration of drug taking, the whole drug history, the number of drugs and the dose varied widely among the patients.

The interviewer was the therapist with the best therapeutic relation with the studied patient. The previously formulated questions served as guidelines only. Method of interviewing the patients emphasized, as far as possible, eliciting the patient's free associations and allowed his genuine, lived-in experiences to determine the content of his communication. This method had been stressed in the present study because it opens a window on qualitative, experiential data, that is, the kind of data consistent with our aim. This psychodynamic method of interviewing, as has been suggested by Nemiah (1989), is quite different from the structured interviews and standardized questionnaires.

RESULTS

Patients' Self-Reports

For the purpose of the present report, we selected from the patients' self-descriptions the statements which were, as far as could be determined, not expressions of: a) subjective complaints which were related to the well-known drug side-effects; b) the known therapeutic effects cited in the literature of psychopharmacology; and c) attitudes and beliefs of the patients towards psychotropic drugs.

The chosen statements are grouped roughly under the following headings:

1- Positive Subjective Experiences.

2- Negative Subjective Experiences.

3- Optimum Relation with the Drug.

I- Positive Subjective Experiences

A- Neuroleptics

١) " الا ستيلازين (Stelazine) هائل فى مفعوله ، ولايتسبب فى درجة ملحوظة من فصلى عن الواقع وعن داخلى ..... باختصار هوه يفض الخناقة الداخلية واشتباك الكيانات الداخلية ، وبكده أستعيد شئ من الاتزان بدون فصلى عن الواقع ".

1- " Stelazine gets a wonderful effect. It does not get me detached from reality or from the inside of me. Shortly, it ceases fire between clashes and conflicts of inner states, and so I get back some balance without detachment from reality."

٢) " الترايلافون (Trilafon) يستطيع تحجيم السوبر إجو أكثر(Superego) من الاستلازين ، فيمكن للأنا(Ego) أن ترى النور و تخرج بنسبة أكثر للحياة ، مع هدوء الخنقة الداخلية والخوف من الضرب (يعنى الطفل الداخلى" Child Ego State " يهدأ ويطمئن شوية) .. يعنى هوه يقلل الاحساس الآتى أكثر من الاستيلازين : انتصار الواجب على اللى نفسى فيه ، يعنى اللى المفروض أعمله على اللى نفسى أعمله ، وأحس إننى بقيت كبير بيأدب الصغير ويعاقبه لو غلط ".

2- "Trilafon can deflate the size of the superego more than stelazine can do, so the ego gets out to light and lives, with a calmness of my internal strain and fear of being beaten. I mean my inner child ego state becomes calm and secure a bit more. Put in other words, Trilafon lowers some feelings more than does stelazine as feelings of the victory of a must upon a lust or what should be done upon what I want to do, and feeling like a grown-up correcting a kid or punishing him."

٣) " الترايلافون (Trilafon) يصلح علاقتى بالناس ".

3- " Trilafon corrects my relations with others."

٤) " بأحس كإن فيه حاجة جوايا بتلحم ... فيه صوت فى صدرى يذكر الله ، وعلى كتفى الشمال شيطان يسبنى ويسب ربنا ... الدواء بيخلى ذكر الله يعلا جوايا ، ويهدى الشيطان."

4- " I feel as if somethings inside me are getting together, fusing.. A voice in my chest was mentioning the name of God and a demon upon my left shoulder was insulting me and insulting God. The pills get the voice louder and clearer and inhibit the demon."

٥) " الدواء يخلليني أحس زى مايكون حاجة جوايا بتتلم شوية بشوية وتتحط فى مكان مش عارفه .. " (يقصد هنا الضلالات) .

5- " The drugs make me feel as if something inside me is getting together, bit by a bit, and moved away somewhere I don't know."

N.B. : The patient is speaking about his delusions.

٦) " كإن جوايا بيهدأ ، بيتصالح على بعضه ..... بعد الدواء بشوية ... أحس إن الدنيا اتغيرت .... المطبخ يبقى كإنه منور أكثر وواسع."

6- "As if the inside of me relaxes and peacefully accepts its parts...and after a while I feel that world is changing...the kitchen looks brighter and wider."

B- Minor Tranquillizers

١) " المهدئات اللى زى الاتيفان والفاليوم والليكسوتانيل (Ativan, Valium, Lexota-nil) تفصلنى فى وقت واحد عن الداخل وعن الخارج ، فتصبح الحياة بسيطة ، والأحاسيس سطحية ، والمشاعر ضحلة ، وإمكان الرؤية الداخلية بعيد جدا . هيه بتدارى خوفى وراء حاجز كاذب يعطينى الأمن والشجاعة المفتعلة لمواجهة الحياة ."

1- " Sedatives like Ativan, Valium, Lexotanil... detach me from my inside and at the same time from outside.. so, life becomes simpler, feelings more superficial and emotions lower. My insight is so far to reach. They (sedatives) hide my fears behind a false shade that gives me an artificial sense of security and courage in facing life."

C- Antidepressants

١) " قبل الدواء زى مايكون فيه حاجة واقفة فى نص دماغى .. حاجة عايزة تعدى من نص دماغى الأيسر للنصف الثانى (الأيمن) بس مش قادرة تعدى . بعد الدواء مابقاش فيه حاجة متحاشة ، يعنى عدت . "

1- " Prior to drugs, it was like something impacted in the middle of my brain. Something that should cross from the left side of the brain to the other side. After drugs, it is no more blocked, I mean it did cross."

٢) " عندما أبدأ أتعب أحس بفكرة بسيطة وصغيرة .. تبدأ تكبر فى داخلى .. أحس أن هذه الفكرة بتكون فى جانب واحد من دماغى أو فى ناحية واحدة .. وتبدأ الأفكار تكبر وتملأ هذا الجانب ... وعندما تزيد جرعات الدواء تبدأ هذه الأفكار تصغر وأحس أنها حاجة عادية جوايا ذى أى حاجة تانية .

2- " When I start feeling ill, I feel an idea, small and simple idea, starting to grow inside me... I feel as if this idea in one side of my brain ...then ideas grow and fill that side... When the doses of the drug increase they start to shrink and I feel them as normal as any other ideas."

II- Negative Subjective Experiences

١) " أغلب الادوية بتتسبب فى موت جوايا ودفنه وعدم الإحساس أو الاهتمام بوجوده. .. واللى بيندفن ده... بتبقى روحى أو النور بداخلى ."

1- " Most of the drugs cause death and burying of my inside, and loss of feelings....what gets buried is usually my soul or my internal lights." .

٢) " أحس إن حاجة بتتسرق من داخلى ... أحس إن حاجة ماتت ولكنه موت غير كامل .. لما أبطل الدواء لفترة طويلة أشعر بها ترجع ثانى .. (فى وقتها أحس أنها ماتت موت

كامل) ... بيبقي فيه حاجز بيني وبين الناس وخاصةالقريبين ."

2- " When I take the drugs for a long period, I feel like something is stolen from my within..like something is dead, but only partial death... And when I stop the drugs for a long time I feel it comes back to life. Also they make a barrier between me and people especially intimate people."

٣) " أما عن الزمن فيكاد يموت وأنا باخد الأدوية : الوقت يمر ببطء جدا ولاحياة فيه ، خصوصا لو كميةالدواء كبيرة وأصنافه كثيرة .. تمشى حياة الناس وتسير وتقف حياتى ولايهمنى هذا فى قليل أو كثير ، كما لا أحسب تحصيل يومى من العمل أو المادة أو الحياة .. ده طبعا بيحصل بنسب تتفق مع كمية وأصناف الأدوية اللى باخدها ."

3- " As regarding time, it looks like dying when I am on drugs. It passes slowly and lifeless, especially if I am on a fat doses or on drug combinations. The people's life goes but mine stops and I feel that nothing is important. This, of course, goes along with how much and how many drugs I take."

٤) " لو زودت الدواء شوية اعصابى تبوظ .. ابقى كأنى نسناس فى علبة مقفولة ."

4- " When I raise the dose a little, it gets on my nerve. I feel like a chimpanzee inside a sealed box."

٥) " ياساتر ... لما كنت آخد الدواء كنت أحس ان روحى ساقعة .. كأن حد لسه مطلعها من الفريزر ولازم أسيبها تفك ."

5- " Oh God!... after taking the drug I felt my soul as cold as ice... like just coming out the fridge and has to be defreezed."

٦) " الدواء خلانى أحس إن جوايا حصان وطالع مطلع ."

6- " Drugs make the inside of me as a horse going uphill."

III- Optimum Relation with the Drug

١) " دلوقت بس نشأت صلة غريبة بينى وبين الدواء .. ما بقاش عدوى إنما بقى صديقى .. أعرف امتى احتاج له ، وما أخافش من أنه يغيرنى كلية ويمحى شخصيتى .... ولما يستمر التحسن بالدواء لفترة ولاتحدث لى نكسات .. ساعتها أفكر فى تقليل الجرعة بالتدريج .. وقد أعود إلى جرعة أكبر لما أكون محتاج لكده .... لكن لن أنسى طول عمرى " الحياة الحية " اللى عشتها لما كنت مقلل جدا فى الدواء وحسيت إنى باستعيد حياتى وعمرى ."

1- " Only recently, a good relation is built between me and the drug. The drug is not an enemy anymore but a friend. I now know when to go for it without a fear of its influence on my personality. And when I start to feel better with no relapses I think of lowering the dose gradually... but I may go back for a higher dose when I feel the need for. But I will never forget the active life I lived when the doses were low..when I felt getting my years and life back."

DISCUSSION

1- We are aware of the great methodological problems and difficulties which are intrinsic to the systematic investigation of the patient's subjective experiences. However, the results of the present study may suggest several hypotheses which need further investigations. One main general hypothesis may be that to obtain optimum effect of pharmacotherapy, not only the nosological diagnosis, but also other several important factors should be considered and assessed continually along the whole course of the treatment. So, in the second phase of this work we have to investigate the relationship of at least the following variables with the patients' subjective experiences of their medications:

a) Age; diagnosis; personality; duration of illness.

b) The type of the drug; the dose; duration of intake; regulatory of intake.

c) The context of taking the drug (milieu); whether the patient is treated simultaneously with psychotherapy or not.

d) The level of adaptation to reality; the range and depth of conscious awareness and insight.

2- Also, this preliminary report may serve to demonstrate certain important points as regards pharmacotherapy:

i) The previously mentioned statements might allow different levels of explanation. What concerns us here is the feasibility of the structural orientation, that is the hypothesis of interpreting the actions of psychotropic drugs as affecting the different levels of brain organizations and, consequently, the corresponding psychic ones. As put by Rakhawy (1990) "We are ... oriented about drug action not only in terms of the chemical substance they can increase or decrease, but also in terms of the holistic consequence on the whole brain as a result of this diminution (or increase) of that specific chemical substance. The language should change from *localization* to *organization*." Many of the patients's experiences could be taken as direct expressions of this approach. We can also notice the differential action of the various drugs on these levels. Also, these statements emphasize the point that the holistic change in the patient as a human being should be stressed in the process of evaluation of drug effects.

ii) Learning to listen carefully to what patients experience when take psychotherapeutic drugs may have the potential to enrich and expand our knowledge of clinical psychopharmacology. Strauss (1989) states the following hypothesis: "We in the mental health field do not listen to what patients experience as well as we think. There are many things that patients are trying to tell us about their subjective experiences that we systematically fail to hear. This greatly limits the accuracy and value of current descriptive psychiatry."

iii) "The clinical field is the first and last milieu where drugs could be assessed." (Rakhawy,1990). In this connection, it might be said that the method of study which elicits qualitative, experiential data is quite important. In these data we may find the key to the neurobiological processes underlying pharmacotherapy. However, this method and the other one, which allows for quantification and statistical manipulation of data, are complementary and mutually supportive (Nemiah, 1989).

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ABSTRAIT

Les Expériences Subjectives des Malades Traités avec les Médicaments Psychotropiques: Est-ce-qu'elles peuvent Aider À Gagner des Perspicacités Nouvelles en Traitement Pharmacologique?

Couramment, il y a un renouvellement prometteur dans les expériences et dans les interprétations des maladies ainsi que dans le traitement des recherches psychiatriques. La question principale de cette étude est :

Si on apprenait à écouter attentivement les expériences des malades, durant leur traitement avec les médicaments psychotropiques; aurait - on la chance d'améliorer notre connaissance de la pharmacologie psychique?

Il se peut-que cette hypothèse clinique, va éclairer cette question.

الموجز

الخبرات الذاتية للمرضى المرتبطة بتناولهم العقاقير النفسية

لقد تعلمنا- ومازلنا نتعلم - من خلال تجاربنا المتنوعة والعميقة مع من يعانون من أمراض نفسية أن نقدر أهمية الاستماع إلى خبراتهم ومعايشاتهم لهذه الأمراض وطرق علاجها . وفى الآونة الأخيرة شهدت بعض الابحاث الطبنفسية العودة إلى الاهتمام بهذه الخبرات والمعايشات ، والنظر إليها على أنها المعطيات الأساسية -كما كانت دائما- اللازمة لفهم متكامل لطبيعة المرض النفسى وعلاجه . ولكن التحدى الهام الذى يواجهنا جميعا هو بالدرجة الأولى تحدى منهجى ، بمعنى كيفية الوصول إلى الطريقة التى تتيح الحصول على هذه الخبرات من غير ما اختزال لها أو تعمية أو تسطيح أو تشويه ، مع العلم بأن كل هذه الأمور الأخيرة كانت - ومازالت - تتم من منطلق الحفاظ على علمية مناهج البحث

ومع اعتبار كل ذلك ، فإننا نسأل أنفسنا سؤالا - هو موضوع البحث الحالى - ألا وهو : فى حالة ما إذا اجتهدنا أن نتعلم حسن الانصات إلى مرضانا وهم يفصحون بشكل أو بآخر عن خبراتهم الشخصية الجوانية التى يعيشونها نتيجة لتأثير الأدوية النفسية عليهم ، نقول فى هذه الحالة هل نستطيع أن نصل من خلال ذلك إلى إحاطة أعمق وأشمل وأدق عن هذه العقاقير والمداواة بها ؟ إن الوظيفة الرئيسية لهذه الورقة هو تقديم بعض الأمثلة المنتقاة من كلام المرضى كمحاولة لتوضيح بعض جوانب هذا التساؤل الهام.