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THE SUBJECTIVE EXPERIENCE OF THE RESEARCH PATIENT: AN INVESTIGATION OF PSYCHIATRIC OUTPATIENTS' REACTIONS TO THE RESEARCH TREATMENT SITUATION

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This study is based upon the subjective reactions reported by 72 neurotic outpatients subjected to multiple research procedures in an ongoing drug study. The procedures included double-blind drug prescription, evaluations by several interviewers, role-playing by treating doctors, unexpected change of treating doctor after two interviews, completion of multiple forms, and observation and recording of interviews. The purpose of the study was to determine the degree to which patients were bothered by research procedures and by the idea and experience of being research subjects.

It was found that 55 of the 72 patients (76 per cent) had no notion that research goals were involved. Rather, they perceived the procedures as diagnostic, teaching and treatment. The most important factors in the patients' perceptions of and reactions to research and to research procedures appear to be prior expectations of help, along with lack of knowledge enabling them to distinguish research from treatment. The great majority of the patients in this study lacked sophistication with regard to what they expected in a psychotherapeutic situation yet they had an overall expectation of "a complete cure" or to be "a good deal better." Thus, 14 patients felt that checking out forms was helpful to them in gaining an understanding of their symptomatology; nine patients felt that the tape recorder was helpful and two patients actually indicated a positive reaction to the use of a one-way screen. From the "realistic" point of view of the research staff, the program appeared to be quite obviously "research," some aspects of which could be seen as at the expense of the "subjects"; the "patients," on the other hand, with their deep-set expectation of help, perceived the program as individually focused on their need for help.

The patients primary concerns appeared to be with the treating doctor, the change of doctors and degree of improvement, rather than with research procedures. Thus, in clinical research, a focal issue for the patient remains the doctor-patient relationship. Careful consideration should be given to this factor in setting up even a brief, controlled psychopharmacological study. Elevating a patient from the role of experimental subject to evaluator of aspects of a research project can help avoid ethical risks and also result in valuable information which otherwise might not be available. The data also indicate the importance of examining afresh some deeply and widely held preconceived biases concerning patient perceptions in clinical research settings.