

DATA MANAGEMENT SYSTEMS IN THE TREATMENT OF PEOPLE WITH INTELLECTUAL DISABILITIES: A MODEL FOR PSYCHOPHARMACOLOGISTS

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As clinicians we monitor our treatment plans based on changes in specific target behaviors. It is not uncommon to find that even the best target symptom data misses significant changes. These gaps may be crucial to understanding responses to both behavioral and psychopharmacological treatments. This paper explores data collection methods that may help close these gaps.

Keywords: data management systems, developmental disability, intellectual disability, mental retardation, psychiatric disorder, psychopharmacologist

Clinicians are frequently confronted with behavioral data that is either ambiguous or fails to provide sufficient information for differential diagnosis or in some circumstances, treatment planning. A significant part of this problem is due to the considerable heterogeneity of most target behaviors. There is significant variability in the typology of many target behaviors due to differences in underlying neurobiology, psychosocial and past learning experiences, and relationship to environmental influences. The problem is further complicated if the clinician relies exclusively on quantitative, single factor data (e.g., frequency of aggressive behavior). From this perspective, quantitative data is still quite useful, but may fail to capture the interaction between other dimensions such as intensity of affective responses, level of physiological arousal, planning/impulsivity, past life experiences, or neuropsychiatric comorbidity.¹ As a result, frequency measures alone may not provide sufficient data to understand the variability seen in challenging behaviors. In many circumstances, overlooking these qualitative differences may be detrimental to effective treatment.

PSYCHOPHARMACOLOGISTS AND DATA SYSTEMS

Typically, clinicians evaluate the efficacy of psychotropic agents based on subjective reports, quantitative changes in specific target behaviors, or improvement on symptom checklists. The psychopharmacologist must also consider drug effects on baseline exaggeration of target behaviors in relation to specific symptoms of a

primary psychiatric disorder (symptoms of mania or depression). But there are many potential problems in combining both data sets. It is often difficult to organize data that integrates changes in the frequency/severity of a challenging behavior with ratings of state-related symptoms such as mood, disturbances in sleep-wake cycles, medication dosages, or serum drug levels.⁹

One solution may involve combining multiple data sets. This methodology will provide the psychopharmacologist with a graphic illustration of the relationship between treatment response and individual pharmacokinetic differences (drug metabolism), behavioral toxicity, or gradual loss of psychotropic drug effectiveness. Using an individual with a seizure disorder as an example, an increase in seizure frequency may reflect a drop in serum drug levels, unsuspected drug-drug interactions, or neurotoxicity. Breakthrough seizures in spite of therapeutic drug levels may represent another set of complications.^{2,5} This sort of data is also helpful in monitoring the effectiveness of treatment for nonspecific SIB and other challenging behaviors,^{6,7,11} as well as primary psychiatric disorders.⁹ In either circumstance, a multi-factorial data collection system that allows these variables to be graphically represented has significant advantages over measures limited to frequency data.

DUAL DIAGNOSES

Since many psychiatric disorders are time limited (episodic), clinicians need a data system that captures the course of phasic events (episodes of depression or mania) with respect to multiple clinical variables. Unfortunately, reliable

acquisition is frequently complicated by many of the same problems that confound psychiatric diagnosis in general:^{4,9}

1. Misattribution of increased target behaviors to ecological rather than adverse changes due to psychiatric illness (baseline exaggeration).
2. Accuracy of psychiatric diagnosis.
3. Proper treatment—right person, drug, and dose.
4. Misreading of adverse reactions.
5. Overlooking adverse responses to non-psychotropic drugs (iatrogenic causes).
6. Diagnostic confusion generated by high rates of comorbid neuropsychiatric disorders.

The high rates of medical and neurological comorbidity among individuals with psychiatric disorders can also complicate treatment decisions. For example, an individual with epilepsy and severe intellectual disability may show a gradual increase in motor activity, repetitive or stereotypic behaviors that are accompanied by changes in diurnal patterns of activity, and subtle reductions in total sleep time.^{12,13} Often, these changes are associated with some environmental event but take on additional relevance in individuals with past episodes of clearly established bipolar disorder.⁸ For these individuals, misattributing these symptoms to ecological factors may delay adjustments in mood stabilizers.¹⁰

In general, a multi-factorial model would be helpful in this situation. With such integrated data in hand, the clinician can compare changes in the frequency specific target behaviors with qualitative changes such as diurnal variations in mood or motor activity, anhedonia, or disrupted sleep-wake cycles. This data may also enhance psychotropic management by providing richer information about the temporal profile of change in target behaviors relative to an emerging psychiatric disorder. As noted above, combined data sets could improve illness tracking and aid in pharmacological decisions such as planning dose reductions in mood stabilizers or elimination of adjunctive treatments (atypical antipsychotic drugs). This knowledge takes some of the clinical guesswork out of the decision to make medication changes and hopefully reduces the risk of relapse and prolongation of psychosocial morbidity.

SIDE EFFECT MONITORS

The early recognition of drug side effects is crucial. Frequently, individuals may present with subtle changes in behaviors that are caused by excessive dosing, elevated serum levels of drugs (e.g., lithium or clozapine), behavioral activation or disinhibition, akathisia, or other forms of behavioral toxicity. For many, there is a time-locked relationship between initiating the new drug (or changing doses) and the emergence of new target behaviors or increases in pre-existing target symptoms that led to the use of the offending psychotropic drug.¹⁴

For example, akathisia may present with increased activity levels, dysphoria, irritability, difficulty initiating sleep or increase in self-injurious behavior or psychotic symptoms.^{3,12} The earliest manifestation may be a declining interval between target behaviors. Subtle changes in frequency of target behaviors, number of behaviors per interval, intervals between behaviors or intensity measures may predate the clinical recognition based on classical symptoms. For example, the clinician may connect recent antipsychotic dose increases or possible new drug-drug interactions to declining intervals between target behaviors. These changes may predate the emergence of clinically recognizable extrapyramidal side effects (EPS) or akathisia. On the other hand, an increase in the interval between behaviors after dose adjustments may suggest that the current dose represents the individual's threshold for response. If such changes happen at lower than anticipated doses (due to slower metabolism and higher serum level), the clinician may use this data to avoid further unnecessary increases in the psychotropic drug.

SUMMARY

With "traditional" data collection systems, it is frequently difficult to compare rates of change in target behaviors with multiple variables without multiple graphs. A system that merges this information into a manageable graphic format would be an exceedingly valuable tool. Such a format would allow the psychopharmacologist to track and compare the behavioral change in relation to multiple variables over time. Having this data would permit a rapid assessment of

psychotropic drug effects as well as provide an early warning system for adverse side events.

At first blush, the use of multi-factorial methods in clinical practice may bring on nightmares about derivatives and integrals in college calculus or multi-variable statistical analyses. But there are distinct advantages to a clinical data collection system that is based on these principles but winnowed down to practical and clinically useful graphic representation.

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