Psychiatric Syndromes by Proxy in Persons With Developmental Disabilities

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Over the last couple of decades, drastic changes have taken place in the philosophy of care, operational systems, and style of services delivered to persons with developmental disabilities in the United States and other countries. Strict monitoring of the quality of services has been required by regulatory agencies, with strong emphasis on the rights of persons with developmental disabilities. Pharmacological treatment has been a focus of attention, with the goal of reducing psychotropic medication usage, and ensuring a clear rationale of targeting specific symptoms, rather than using these medications for the purpose of sedation, chemical restraint, or staff convenience. These restrictions in pharmacological treatment highlighted the need for accurate symptom-reporting, sound diagnostic procedures, and specialized training of staff from various disciplines.

REACHING A DIAGNOSIS OF MENTAL ILLNESS IN PERSONS WITH DEVELOPMENTAL DISABILITIES

Although there is a general consensus that people with intellectual disability are at an increased risk of developing psychiatric disorders compared to the general population, the reported rates have shown high variability. Campbell and Malone reported prevalence rates of comorbidity of psychiatric disorders and intellectual disability in community and clinical populations from 14.3 to 67.3 percent. Also, the nature and severity of the mental illness is often difficult to pinpoint, due to the communication problems with this population, and their inability to provide reliable subjective reports of their symptoms. Studies have shown that psychiatric disorders such as schizophrenia and affective illness present differently in this population, and could potentially be misinterpreted by caregivers or even professionals. Similarly, individuals with Autistic Disorder, as specified in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision show qualitative impairments in communication. Although various scales and instruments have been developed to assist with the diagnostic assessments of these individuals, the use of a "third person" is often inevitable. Whether it is the family of the individual or the direct care staff, their input is usually based on their personal observations, experience, viewpoints, and interaction with the individual, with considerable degrees of subjectivity.

MEDICATION POLICIES AND USAGE

The use of pharmacological treatment to control maladaptive behaviors in persons with developmental disabilities had been common practice in institutional settings, whether acutely as a chemical restraint in crisis situations, or long term, to suppress chronic behavioral problems. A study of psychopharmacological practices over the past decade showed that while a large number of medications were prescribed for various psychological disorders and behavior problems, most drug administrations were not behavior or psychiatric symptom specific, and were rather given to suppress a myriad of aberrant behaviors.
thus chemically restraining the individual in question. These challenging behaviors primarily consist of violence against peers or staff, disruptive behavior, resistance to direction, and destruction of property. The advent of patient-focused policies and “best practices” emphasized the inappropriateness of this practice, and implemented strict monitoring procedures and guidelines for proper use of psychotropic medications. These guidelines often require the involvement of the interdisciplinary team, professional reviewers, and human rights officers in the decision making about pharmacological and non-pharmacological treatments.

**Symptom Reporting and Perception by Caregivers and Professional Staff**

In developmental centers, community homes, and other residential settings, direct caregivers spend the most time with individuals with developmental disabilities. Despite the advances of assessment techniques, accurate symptom-reporting in these individuals is often difficult. Although caregivers’ reports of maladaptive behaviors are usually reliable, the perception of psychiatric symptoms and expectation of effects from medications is sometimes unrealistic. This difficulty could be probably attributed to one or more of the following reasons:

1. **Increased risk in the work environment:** Due to the past history of abuse of individuals with developmental disabilities by staff, and the resulting litigation, the new regulations pose very strict and complex requirements for the protection of the individuals. Caregivers often find themselves exposed to physical assaults, legal risk, loss of job security, and not uncommonly, false allegations. The new regulations often seem to grant the individuals excessive freedom, little or no accountability, and the upper hand of credibility, to the exasperation of caregivers. The reporting or perception of behaviors as psychiatric symptoms is sometimes a desperate attempt to deal with unmanageable behavioral risks.

2. **Lack of knowledge of psychiatric symptoms by caregivers:** individuals with intellectual disability often present with aberrant or bizarre behaviors. Those who are verbal could also present with stereotypic expressions that characterize their thought pattern. These features could easily be perceived as mental illness. Unjustified violence and aggressive behaviors may be signs of a bona fide psychiatric disorder but are not necessarily so. It is sometimes the expectation of caregivers that psychotropic medication will correct most of these behaviors. On the other hand, they may underestimate or be unfamiliar with the potential adverse effects of psychotropic medications.

3. **The tendency to continue the same medications indefinitely:** direct care or professional staff may not want to “rock the boat,” especially if an individual has not been a management problem, but had a history of challenging behaviors in the past. It is a common conception that if the medication is reduced or discontinued, the same behaviors will inevitably recur.

4. **“Carry over” information from past records:** it is not unusual for professional staff to endorse the diagnoses and symptoms that have been previously reported. Although this is not necessarily bad practice, especially when past records are the primary source of available information, the clinical picture of individuals may change over time.

5. **Misinterpreting behaviors or incidents after medication reduction:** Although a clear rationale for discontinuation of the medication may have been given by medical personnel, other staff may perceive challenging behaviors or unrelated incidents as a recurrence of psychiatric symptoms.

**Does Mental Illness Result in Severely Challenging Behaviors in People With Developmental Disabilities?**

In 1993, Rojahn et al. conducted a study on a large population with developmental disabilities in New York and California, to investigate the correlation between psychiatric diagnoses and severe behavior problems in this population. The study focused on nine major DSM-III-R psychiatric categories (or their equivalents), and severe forms of aggressive behavior, property destruction, self-injurious behavior, and stereotyped behavior in individuals 45 years old and younger with intellectual disability of all levels of severity. They found no compelling evidence of correlation between the diagnoses and the behaviors, and reported that the results were consistent across databases. However, this does not necessarily indicate that the above mentioned behaviors
cannot occur in the course of mental illness, since they can be found in psychotic and affective disorders in individuals within the normal range of intellect. In people with severe developmental disabilities, challenging behaviors could be the atypical presentation or secondary feature of a psychiatric disorder. Additionally, irritability may be a mediator of aggression and self-injury associated with psychiatric disorders such as depression and mania in individuals with intellectual disability, and may also be associated with central nervous system dysfunction in the absence of a classic psychiatric disorder. Furthermore, behavioral deterioration could present as a form of tardive akathisia, or pharmacological rebound after anticholinergic discontinuation. Such presentations may complicate the psychiatric diagnosis, and suggest a relapse of mental illness when difficult behaviors are encountered. On the other hand, the DSM-IV-TR clearly states that “neither deviant behavior (e.g., political, religious, or sexual) nor conflicts that are primarily between the individual and society are mental disorders unless the defiance or conflict is a symptom of a dysfunction in the individual.” Accordingly, a balanced approach must be exercised when judging whether or not a challenging behavior is associated with a psychiatric disorder.

Feigning Psychiatric Symptoms by Proxy

Reporting questionable psychiatric (or physical) symptoms by caregivers could be the product of misperception in good faith, or feigning. The latter case is classified under “Factitious Disorders” in the DSM-IV-TR, and the presence or absence of external incentives differentiates factitious disorder from malingering. Also mentioned is “Factitious Disorder by Proxy”: the intentional production or feigning of physical or psychological signs or symptoms in another person who is under the individual’s care for the purpose of indirectly assuming the sick role (without a clear external incentive). On the other hand, in malingering by proxy there is an external incentive for the caregiver, and the individual (usually a child) is instructed to feign symptoms. Although “Malingering by Proxy” is not mentioned as such in the DSM-IV-TR, the communicative limitations of individuals with developmental disabilities makes them quite vulnerable to being an object of malingering by others. In this respect, they are similar to the pediatric population. Whether by direct reporting or by instructing the individual to make a specific complaint, the incentive is generally to have a medication administered to the individual, with the hope of suppressing the challenging behaviors. A possible scenario is to claim, by false interpretation or false reporting, that the individual is hearing voices, not sleeping, being “paranoid,” “manic,” or “psychotic.” In general, feigning, exaggerating, or reporting unfounded symptoms by a caregiver is not ethical.

Suggested Practical Approaches

1. Education. It is important that the people involved in the care of individuals with developmental disabilities have adequate understanding of the nature of their problem, and the types of behaviors that can be considered part of a mental illness. While it cannot be expected that caregivers make a “differential diagnosis,” basic principles and guidelines can be helpful. It is also important to have reasonable knowledge about what to expect from the effect of medications. Professionals also need to continually familiarize themselves with the diversity and peculiarity of this population, and keep abreast of current research and advances in this field.

2. Symptom-monitoring and verification. Thorough assessment of the individual in question is paramount, including past history and records. Personal observation by the examiner, as much as feasible, is indispensable in the case of questionable reports. Obtaining collateral information or observational reports from several sources and staff members could be valuable in reaching a conclusive picture. Medication adverse effects or withdrawal symptoms may contribute to the presentation, and should be considered.

3. Medical work-up and psychological testing. Medication blood levels, urine drug screen, or other laboratory tests may help clarify the picture. For example, confusion and hallucinations may be the result of overmedication. Psychiatric scales and psychological tests could be used to clarify the diagnosis, and document the presence or absence of a set of clinical features.

4. Adequate training of caregivers. It is important to equip them with efficient support techniques for handling challenging behaviors will help minimize risky situations and the
perceived need for restrictive pharmacological approaches.

5. **Good communication.** A working relationship, efficient reporting mechanism, and mutual understanding between various disciplines is necessary for adequate care of the individuals served.

**CONCLUSION**

When a psychiatric disorder is being considered in an individual with a developmental disability, caution should be exercised in examining and interpreting available data. Staff education, training, and good communication in the work environment are essential to achieving appropriate management. Ethical considerations and conscientious reporting must be emphasized. As a rule, the most important consideration should be the best interest of the individual.

**REFERENCES**


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