Pervasive Developmental ("Autistic Spectrum") Disorders: Treatment Issues

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Abstract

In the treatment of severely disturbed children and their families, the key words now are integration and cooperation in the gathering of knowledge and provision of services. Biological, systemic/social, and psychodynamic schools of thought are approaching some agreement. Outside of academic settings, those of us on the "front lines" must use all of our knowledge, and adapt quickly, even as we experience the trauma of the child and family.

Findings in the neurosciences in the past few years have shown us how the brain is, indeed, in part socially constructed, and have supported decades of careful clinical observation and treatment based on the psychoanalytic method. Historically, this method emphasizes all data, including not just those that fit a particular theory or trend. Like any other approach, it can be misapplied. At its best, it informs and guides our treatment of the child within the matrix of relationships in the family and in the larger social sphere.

Too often, such loftier, long-term goals give way to the pressure for the quick, short-term "kick" to the system. For the medical practitioner, this can lead to brief "trials" of a series of medications under otherwise uncontrolled conditions that are less than optimal for safety and objectivity.

Issues in the Approach to Complex Children with Pervasive Developmental Disorders

In this paper, I address the experience that my colleagues and I have acquired through work with a variety of children referred to the Youthdale Psychiatric Crisis Service. Because of the referral pattern, these children have already received extensive assessments and treatment interventions. The term Pervasive Developmental Disorders (PDD) refers to a very heterogeneous group of children who may present with difficulties with communication, social relationships, and idiosyncratic interests.

The children described may or may not be representative of a larger diagnostic group, in terms of characteristics and treatment response. Our experience with treatment response in crisis is that it is quite idiosyncratic and may result as much from perturbations as from specific interventions.

Diagnosis

The subject of PDD is painful and frightening. Those on the front lines require a balance between dry, abstract ideas and the feeling of working directly with such children. In our setting, we have the advantage of a contained, safe place in which to get to know children and families more intensively. Like other professionals who work in the field of developmental disabilities, my colleagues and I work under tremendous pressure. There is a great expectation to provide a "cure". There is often pent-up frustration in families regarding previous experiences with professionals. We immediately have to deal with high expectations, working with families to formulate reasonable goals. At times, we are asked simply to provide a diagnosis that will improve access to other services. But we must be careful that the diagnosis we give does not serve to interfere with the parent's sense of continuing to learn about the child and to function in a parenting role. At times, hearing the diagnosis of PDD can be a shock, and implies to the parent that there is little hope. For example, one mother demanded at a clinic visit that I diagnose her son. Challenged on whether giving a diagnosis of PDD right then would indeed be most helpful to her as his mother, she burst into tears, pleading, "I want my son back."

In initial meetings, we may watch helplessly, as the child suddenly attacks the parent (often the mother) kicking, biting, or pulling out her hair. One mother described the assault as though she were in the middle of World War II. In desperation, parents seek anything that will help, but they also fear potentially dire consequences.

Medications

A psychiatrist familiar with children with the PDD diagnosis will have in mind more than twenty different medications that can be used. These include those in a number of general categories including antidepressants, anxiolytics, antipsychotics, anti-arousal medications, anticonvulsants, stimulants, and other newer medicines. Virtually all are used in PDD for targeting specific clusters of behaviours that may have various, and more or less understandable, causes. Adequate studies of these medicines in children with PDD are few. The medications may be added, one to another, in a spiraling process, as the child "breaks through" helpful effects of one medicine after another, or exhibits "symptoms" of one "disorder" after another. For example, from our experience, we are aware that some children have first received a diagnosis of Attention-Deficit/Hyperactivity Disorder, and then a diagnosis of Obsessive Compulsive Disorder as repetitive movements manifest, followed by a diagnosis of PDD as social deficits become more pronounced. A given child may have been on a dozen or more different medications, and may present to the clinic on three to five, simultaneously. This raises not only ethical issues, but also questions about what medications are actually doing, individually and in interaction (Furman, 1996).

It is not inconceivable that the transient response to a new drug may have more to do with nonspecific perturbations of the nervous system rather than with specific neurochemical effects. I recently came across a story in an article by Dr. Thomas Kramer (2001), which questioned the rationale for using two different medications, which have opposite pharmacological effects, but nonetheless seem to produce the same result:

A major network radio transmitter broke down. An expert was called in. The expert walked up to the transmitter and stared at it for a few minutes. Then he walked in a large circle around the transmitter. Finally he stopped, picked up his foot, and sharply kicked the transmitter. CBS was back on the air. The next day, CBS got an itemized bill from the outside expert. It said, “One kick, $1. Knowing where to kick, $9999”

Perhaps, Kramer goes on, it is not the specific pharmacological effect, but "simply jolting the system", that brings about the desired change.

Importance of resources

Even the most careful and knowledgeable use of medications can be of limited value in the absence of appropriate services. For example, I have been following a nine-year-old boy who lost considerable language and social ability secondary to seizures at age two and one-half. He presents within the PDD diagnostic range. He lives approximately three hours away. Medication trials are extremely difficult to carry out at such a distance, with phone tag and lost FAXES being the norm, along with limited availability of appropriate support services, and no psychotherapy available, of any sort.

I think we all agree that necessary resources include enough experienced and well-supervised professionals who together know enough about a wide variety of children and families, about specific treatments, about medical disorders and medications, and who can relate, in a timely fashion, as people and as professionals, to those in immediate need. We may require safe places in which to do this work, including residential and specialized hospital settings — available on an immediate basis if necessary, and closely coordinated with other services. There needs to be education, consultation, relief, support, and, above all, recognition of the extraordinarily hard work that such professionals do. Furthermore, the parents need to be included as part of the treatment team. As I speak to parents, I hear about their traumatization from assault, burnout and despair, frustration and fear of disaster. Follow-up of parents as well as of their children is woefully inadequate, often for reasons that are beyond the control of the professional.

From theory to practice

One approach to improving treatment for children with PDD is to find a general theory that can "explain" what we experience from the child and family, at an abstract level (Rapin, 1999). Those of us who must respond quickly to crises, can find that uncertainties can outweigh certainties. One frustrated and worried pediatrician told me, with regard to one particular child, "there is no single person on earth that knows all the medications this child has been on." Often, I see children who have been on at least a dozen medications prior to seeing me. After they see me, they will likely see yet another specialist, and perhaps another after that. Often I don't even know what happens to them.

To reverse this trend, we require centres of expertise, teams, various levels of residential and hospital care, ways of tracking children and their families, and regular, careful, and useful follow-up. But most important is respect for and recognition of the parent's central role. If we advance too quickly in our application of knowledge, we may leave the parent feeling out of touch and out of control. Parents must assimilate vast amounts of information under situations of stress. If we do not consider their feelings, they may leave us abruptly, searching for help that will re-include them. This may be described as "doctor-shopping", but represents something more fundamental -- the need for a professional who feels like the parent.

The importance of communicating with the child

Despite the presence of social deficits, I can't recall a child who, at some level, was not acutely aware of something characteristic about the parent, or responsive, in some way, to the state of stress, tension, or even enjoyment in the parent. Even severely impaired children have a psychology which overlaps that of normal children. For example, a young child with a rare genetic syndrome producing severe visual and social impairment, commented that my office was "strange", and that I myself looked like someone from a far-away country. Thinking of the psychological mechanism of projection, I wondered if it were *she*, in fact, who felt strange, and, relieved, she nodded vigorously in the affirmative.

The complexity of disabilities

Disabilities are not monolithic or irreducible. They must be further probed and explored, to reveal their components and causes. Diagnoses and labels may become self-fulfilling. Rage and aggression in any child can have multiple determinants and meanings. Children may devise their own ways of mastering perceived abandonment or separation, through self-organizing and self-soothing behaviours. For example, a girl adopted at age one and one-half from an eastern European orphanage was observed, at age four, mechanically climbing on a table, throwing down a pencil, climbing down, picking it up, climbing back on the table, and so on, in a way that was chillingly reminiscent of how a normal infant might induce the parent to participate, in a pleasurable way, in such a "game".

Complexities of assessment

To the busy clinician, a typical day can feel like a series of *kicks or jolts*. Sometimes it feels like being a constant bystander at a series of hit-and-run accidents. What can we all do about what we agree is a serious problem?

Dr. Michael Rutter (1999), in his Emmanuel Miller Memorial Lecture, spoke about evidence-based medicine as follows: "It is appropriate that we are challenged to demonstrate that we are using methods that work and that we are not neglecting approaches that are even more effective. Nevertheless, there are dangers if we adopt too mechanical, and too simplistic, an interpretation of "evidence-based medicine". . . . "Where, then, do the dangers lie?"

"First, the essence of research lies in the process of *problem solving* and not in a mere provision of a set of factual answers."

Assigning a diagnosis includes assessment. The process of assessment must be interactive, rather than descriptive. Many of us have felt that we can *identify* (which is different from *assessing*) a child in the autistic spectrum in a matter of minutes or seconds. However, the more I see, the more I begin to question the wisdom of this idea. The spontaneous expressions of the child must be understood in a context. There must be opportunity to assess the child’s ability to adapt, and to respond to overtures to engage. By the time they see a specialist, many children have a collection of diagnoses and medications they have already been on. Clinical phenotypes of children in the autistic or PDD categories tend to be quite heterogeneous. They may have experienced prenatal alcohol, drugs, or other teratogens, may suffer from familial genetic syndromes or mutations, and, like other children, may have suffered from neglect, trauma, head injury, or have other neurological syndromes. The relationship of the ever-lengthening list of diagnostic assessments to the actual child reminds me of the hair follicle, or cell. As you know, the hair cell produces proteins that are wound together and extruded. Over time, this forms a long strand, which, though delicate and beautiful, is, nonetheless, in itself, dead. It is the *tiny hair cell* that is alive. In the clinic, we are often presented with a thick chart containing numerous assessments, a lengthy list of problem behaviours, and dry, lifeless, descriptive diagnostic labels, along with a litany of seemingly fruitless attempts by professionals to help. It is as if we are confronted by a mass of thick, tangled hair, with little evidence of life, creativity, and possibility. The *child* is the live hair cell.

Research

Rutter continues: "A creative imagination is as fundamental as a rigorous testing of hypotheses. Research comprises a telling of stories about how mechanisms in nature might be operating, then using experimental-type strategies to test the ideas expressed in the stories, to compare alternative explanations, and gradually, in an iterative [back and forth] fashion, to move progressively closer to what might be the truth."

I think, here, he is stating the most important point. As I said at a meeting involving four Ministries in the government of Ontario, "There are no Ministries in the mind." What I was referring to, and I think Dr. Rutter refers to as well, has been a disservice that we, collectively, have done to children and their families. Rather than attempting to integrate and synthesize, we have tried to reduce and distill complex problems to simple components. Rather than joining together and working out our differences in understanding and temperament, we professionals have split ourselves up into component disciplines, competing with one another other for academic advancements and scarce research funds (and who can blame us?).

Treatment

We may neglect that the child is a being, a person, within relationships, however troubled. We have cut ourselves off from our roots, clinically, academically, and as human beings. In our zeal to "cure", we have also competed with parents, to prove our worthiness, over who can better help the child. An educator and child therapist, Erna Furman, commented that if we try to take over the parent's role, we are doomed to failure in our efforts to treat. If we treat the child-parent *relationship*, as opposed to the individual *patient*, we are more likely to succeed in our efforts. A mother complained that her delayed toddler refused his antipsychotic medication, prescribed for his tumultuous behaviour. She related, somewhat guiltily, how she had been sitting on him twice a day, forcing the medication into his mouth, in order to comply faithfully with directions. Perhaps she and her child would have been better off without such intervention.

The complicated child responds best to our relationship approach where, first and foremost, we proceed from the parents’ point of view. As well, some parents surprise us, when we invite them, in their own language, at their own pace, and in a comfortable setting, to tell us about themselves. For example, I asked a father (who, it seems, had said nothing for years to any practitioners) what he liked to do when he was his boy's age. In barely audible, monosyllabic answers, he began to slowly elaborate, with increasingly expressed feeling, and increasing spontaneity, a whole world of concerns, worries, and wishes for his child.

The important past

History gathering from the parent is a complex but essential task. It is also essential for us to discover or rediscover the history of our own field of endeavour. Dr. Rutter continues: "... the most important thing is not to know which of our current methods are best but, rather, to have a means of moving forward to develop even better methods in the future"..."Many of the greatest clinical advances have relied on research from the past that, at the time, seemed to have little clinical relevance."

Past and future directions

I am reminded of MEDLINE date cutoffs which automatically eliminate early studies that current studies may neglect. Recent neuroscience research, amply represented in MEDLINE, shows us intriguing systems of brain components which interact in ways that change with experience. The brain arises out of the body and reflects the state of the body, within the environment. Through an unfolding developmental process, the mind develops out of the brain. But the mind retains the traces of the early struggle to emerge from the flesh. The resulting neuroanatomical and biochemical pathways and networks are relatively stable and unchanging, and based on adaptive interactions with the environment within relationships. But they are also changeable, through learning, experience, and relationships.

This is not really new to us. Prior to MEDLINE cutoffs, one finds a rich clinical literature, both describing syndromes in highly integrative ways and documenting treatment experience in great detail. Careful studies based on the psychoanalytic method originally expounded the broadest, most inclusive view of the person and the mind, within relationships (Schilder, 1964). The psychoanalytic method included biology, and arose out of the state-of-the-art neurophysiology and neuroanatomy of the day. It is only in the past few years that the available methodology has given us ways to test and to confirm the earlier ideas about the complexity of mind. The theoretical battle is now essentially ending. We are living in an exciting time of integration and synthesis.

The integrative approach is needed now more than ever. Medications have been disappointing (Posey & McDougle, 2000), sometimes with more unwanted side effects than benefits. Our hopes for a "cure" have certainly been very high and probably unrealistic. After all, one does not treat all patients with fever or chest pain with the same medication. The neuroscience findings applicable to PDD are ahead of clinical practice. Clinical practice, in turn, is ahead of clinical research. "Well-designed" research protocols may exclude complex children. Intensive behaviour interventions requiring many hours per week can bring about changes, but through great effort, and in ways that we do not fully understand. Brain imaging falls short of telling us what is wrong with the child. Normal-appearing brain can be profoundly dysfunctional. Alternatively, children with gross brain deformities may appear basically normal behaviourally. There appear to be significant capacities for adaptation (plasticity) in some individuals. We do not know what the limitations are for what is achievable, for any particular child who presents with diagnostic criteria for PDD.

Children and families plead for relief from suffering. However, the many academic, social and economic pressures we experience may actually impede progress.

Dr. Rutter concludes regarding the psychiatric pioneer, Emmanuel Miller: "... he would... be concerned to ensure that these advances feed through to community services and do not remain confined to tertiary care specialist centres." ... "I think he would be troubled by the extent to which evangelists among both researchers and clinicians have sometimes made excessive claims. Perhaps, too, he might be worried lest a market economy emphasis on destructive competition may foster such claims."

Conclusion

Back to the radio transmitter. We need to know where to kick, but also when, how, and why? And to be able to. And to have the courage to "kick", or not to. And what happens the next day, when the transmitter shuts down, yet again? Where will the "expert" be?

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