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ABSTRACT

Based on interviews with several hundred parents, teachers, physicians, and hyperkinetic children, the paper addresses the scope and nature of the social aspects of the psychopharmacological treatment of hyperkinetic children. Excerpts from interviews are given. Reported among findings are an inability of individuals who are charged with the responsibility for the delivery of services to children to develop the working agreements necessary to provide a cohesive and rationalized approach to the delivery of those services; that parents and physicians each tend to nominate themselves as legitimate and dominant; that both parents and physicians see the teacher as rarely dominant and often nonlegitimate, and teachers concur; and that teachers also tend to agree with parents in their definition of who should be dominant and who should be legitimate. (SBH)

CREATING AN APPROACH FOR UNDERSTANDING THE DIAGNOSIS AND TREATMENT OF HYPERKINETIC CHILDREN

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The theme of this symposium is the use of psychopharmacology for children and adolescents. It is certainly useful to think about what the future holds with regard to the development of new psychopharmacological products. Each new product represents a challenge. Whether we consider psychopharamacological technology as "Pandora's box" or "better living through chemistry," the box has been opened and the chemicals are among us.

As we consider the ways in which we should respond to the new developments in psychopharmacological technology, it is instructive to consider how we have responded to those techniques already existing. Perhaps the most noted use of psychopharamacological technology for children and adolescents is the use of stimulant medications for the treatment of hyperkinesis. Over the past fifteen years, our society has struggled with the problems of applying an existing psychopharmacological technology. We think there are lessons to be learned from this experience. These lessons can only be learned if we can pull back from ideological or disciplinary myopia.

The fundamental question in the minds of those concerned is: Is the diagnosis of children as hyperkinistic, and their treament with stimulants, a beneficial or a harmful activity? Few would be categorical in their endorsement or condemnation. Both critics and proponents recognize that the diagnosis and treatment of hyperkinetic children is fraught with problems. Both camps acknowledge that there are problems in case finding. Both recognize that there is a failure, at times, to employ approaches which address the range of problems encountered by the hyperkinetic child. Both recognize problems in the management of the monitoring and the maintenance of the regimen. Both acknowledge some possibility (though to different extents) that treatment may lead to labeling that works to the detriment of the child.

We believe that these problems are not problems that can be understood and solved by additional pharmacological or medical research. What is required is an understanding of how the people who are involved in decision making relative to these questions function and interact. A new approach toward hyperkinesis and its treatment is required to advance our understanding. This approach is not confined to the medical domain but includes it in a broader social perspective which needs to be articulated and elaborated as a basis for empirical research and policy for the treatment of hyperkinesis.

We have just completed a research on hyperkinetic children that involved interviewing several hundred parents, teachers and physicians of hyperkinetic children, as well as the hyperkinetic children themselves. The fundamental premise of this research was that the diagnosis and treatment of hyperkinesis is a social act involving medical and educational aspects, for if hyperkinesis is confined to the technical perspectives of medicine or education the problems which have been perceived can never be resolved.

We have been uncomfortable with presenting the notion of a social approach because it seemed obvious to us and clearly implied by much of what is said and written. In ways which conjure the expression "teach the whole child," the attempt to focus understanding of hyperkinesis on the "whole social process" may be too easily dismissed as a slogan without realizing what is involved.

We would like to share with you what is involved when we recognize the scope and nature of the social aspects of the treatment of hyperkinetic children at the two levels that we have experienced it. The first is in the words and feelings of parents, teachers, physicians and children who have struggled with the situation. The second is the more antiseptic and systemic picture which emerges from the analysis of our data. In this presentation, we will be able to present only a small but representative portion of the data we have available.

In the course of our interviews, we have spoken with parents who have told us of the years in which their children's problems have gone unrecognized by the school system. These same parents have said that ground gained sometimes is lost when the child changes teachers. We have heard of the battles between physicians and teachers in which the child becomes the unwitting victim. We have been informed, in painful detail, about the children placed on stimulant medication by the physician whose regimen is strongly opposed by the teacher, with the result that the child and parents are caught in a tug-of-war between experts. We have seen bewildered, unhappy and frightened teachers equipped with too little information about the condition of the children in their care, and the treatment being given those children, who feel hopelessly isolated from the physicians and the medical treatment being given these children. We have seen these and what strikes us as just about every other conceivable consequence of the lack of coordination. While the words that I am about to read, from a parent describing her concerns about the treatment of her child, carry some of the flavor of frustration and anxiety, you would need to hear her actual spoken words to grasp the feeling that accompanied them:

> I think the only thing we can say is what we've said many, many times before. There is not a very good home, school relationship with either a physical or emotionally handicapped [child]. I would almost like to see some direct form of communication, at least between the home and school. You try and you try and they just won't do it. Maybe some method of forcing the teacher to make regular reports...whether a child has a problem or not. I think it's important.

Although parents may be the most strongly affected by the lack of coordination and may feel the deepest personal sense of frustration, even anger, at the inability to work things out, similar feelings have also been evident in interviews with teachers and physicians. The following comment was made by a teacher at the end of an interview:

> This is the first time that I've had a child on Ritalin, and I've had many kids that I guess people would say are hyperactive, like ---, and, as I say, maybe the medication has him calmed. To me, he has more of a learning disability. But the thing is, I would like to hear from someone other than his mother that the child is on medication,

> especially when you receive a child that's on medication when you receive him. I received this child. No one said anything to me about it. The mother told me about the medication. She sees that he has it every school day, but I think the doctor should tell me, or at least get in touch with the nurse and have her pass it on to me, because, like I say, I don't know if it's helping him or what.

Note how this concern is reflected in the words of a physician we interviewed:

> I think that one thing that I would like to see come out of this research is the meeting of two needs. Number one, and I am saying this as a selfish need, I wish there were a learning disability team. I don't mean to get out of my realm, but I sometimes find myself doing, you know, treating kids with learning disabilities when I feel that someone else could do it better. I don't like to treat kids for congenital heart disease when we have a cardiologist in town. I don't like to be a traffic cop. I'm a primary physician, and I really should take the bull by the horns, and I do, but sometimes I wish we had a team where a kid who has a learning disability is seen by a social worker, psychologist and an education specialist - not necessarily that child's teacher, but someone whose got a Ph.D. I mean someone whose got some maturity as well as some experience, and then a pediatrician and a neurologist. If all of them got together and then had a teacher and mother come in and say "hey, this is a problem," I'd feel better. The second thing I think is we have to change our attitude toward kids who have learning disabilities. I think that we talk a lot about behavior modification but, see, what we're trying to do is to get the kid to be more like what we want him to be, and maybe the kid is the way he would be, but maybe our attitude toward him should be a little different.

Our interviews with children graphically displayed the extent to which the children's attempts to cope with their diagnosis and treatment for hyperkinesis involved social and psychological factors far removed from the formal medical diagnosis and prescription for the formal educational programs of the child. One child interviewed responded to our questions in the following fashion:

> Q: Did you ever talk to your teacher, or parent or doctor about changing anything about your medicine or pills?
>
> A: No. I have no control over it.
>
> Q: Did you ever talk to your parents, or teacher or doctor about stopping the medication or pills?
>
> A: No. If I said that I don't know what they'd say.
>
> Q: Do other children ever say anything to you about the medicine you take?
>
> A: Yes.
>
> Q: What do they say?
>
> A: I don't want to say it.

Q: Do other children treat you unfairly because you take the medication?

A: Yea, some.

Q: What?

A: I don't want to say it. Does this go to my mom or dad?

Q: No.

A: Where does it go to?

Q: Western Michigan University. We've talked to a lot of other boys, and girls too, and this is the way we can learn a lot of things about how you feel about taking the medicine.

A: I feel terrible.

Q: Do other children ever tease you about taking the medicine?

A: Uh-huh.

Q: What do they say or do?

A: They just say mean things. I don't want to say them.

Q: Do your brothers or sisters or parents ever say anything?

A: Not usually.

Q: Do your brothers ever treat you unfairly?

A: Oh, yea. And they also get beat up.

Q: What do they do?

A: Sometimes, they say "pill freak" and they don't live very long.

These quotes are illustrative of the information provided us by parents, teachers, physicians and children. When our respondents talk of their experiences with hyperkinesis, they speak of it in terms of the social, interpersonal and educational factors that comprise their reality. Neither the condition nor the treatment is confined to the medical aspects. The merging of the various aspects into a single life experience is evident. There is a sense of frustration, anger and sometimes fear that runs through many of the interviews. Yet, in the same interviews, there is often an expressed belief that the diagnosis and treatment of the child was correct and helpful.

The data we have analyzed were gathered about slightly over 200 hyperkinetic children in a large urban public school system. We interviewed the parents of these hyperkinetic children, their teachers, their physicians and, finally, the children themselves. This approach allowed us to compare parents, teachers and physicians as samples and allowed us to compare the parents, teachers and physicians of individual hyperkinetic children as sets of adults caring for a hyperkinetic child. Our interviews provided information on the social process, roles, social history of diagnosis and treatment and attitudes and beliefs about the diagnosis and treatment of hyperkinesis.

In our research, we used a social systems orientation which involved the three critical systems that are entailed in the diagnosis and treatment of hyperkinesis: the family system, the medical system and the educational system. One of the concepts which is directly derived from social systems orientation is role. In our work, we have taken the most widely accepted perspective on role, which is to consider role the expected behavior of persons to hold specified positions in a social system. The concept of role provides a useful tool to assist us in identifying the specifics of one of the critical aspects of the total social process entailed in the diagnosis and treatment of hyperkinesis. This aspect is the way in which the various key participants define their functions and the functions of other key participants. When role is used as an analytical tool, we can examine the extent of cohesiveness among the medical, educational and familial elements. As we listen to the litany of problems which are recited by those who have been involved in the treatment of hyperkinesis, we believe many can be understood by a role analysis focused on the coherence of the involved systems.

For example, for one of the items on the role inventory which reads: "Should a hyperactive child being treated with medication have an explanation of the medication?", the interview inventory was conducted so that the respondents could indicate whether they believed such behavior should be carried out (inclusion), who should be the person with prime responsibility for carrying out this behavior if it were to be carried out (dominance) and all other persons who were perceived to be legitimate with regard to the enacting of the behavior (legitimacy).

These data were gathered from the parents, teachers and physicians of the identified hyperkinetic children. They were combined into "sets" so that we could gauge the amount of agreement in the proposed behaviors for each of the hyperkinetic children among the salient adults in his/her social environment. We then analyzed the data by dyads. For each child, there were three dyads: parent/teacher; teacher/physician; parent/physician. In each dyad, we measured the amount of agreement.

[Table One Here]

Inspection of this table shows that there is uniformly high agreement across all three dyads in the inclusion dimension (approximately 85%). This reflects, in part, the nature of the items. We provided items which were conventional and reasonable in the diagnosis and treatment of hyperkinesis.

In the dominance dimension, the agreement drops appreciably to the upper 30% - lower 40% range. The percentage of agreement is even smaller for legitimacy (18-22%).

What these data reveal is that the agreement among the dyads breaks down on the issue of who should be involved relative to the expected behavior and who is the person of prime responsibility in carrying out the behavior. There must be agreement on all three dimensions of role in order for there to be social systems coherence. There must be agreement that the specified behavior is necessary, that there be a specific responsibility in initiating this behvaior, and that there be agreement about others who should be involved.

The extent of disagreement in the latter two elements of role does not necessarily mean that the behavior will not occur, but it may mean that it occurs in a disjointed, inconsistent or conflict ridden fashion with the participants pulling and tugging for "proper" expression of the behavior according to their own beliefs. This is not inconsistent with the expression of conflict in part of the literature and is a powerful commentary on the need to understand the full social aspects of the diagnosis and treatment of hyperkinesis in children.

We think that in understanding the ways in which the development of cohesive approaches to the diagnosis and treatment of children can break down, there is an important difference in situations wherein the breakdown occurs over the question of whether something should or should not be done in contrast to those situations wherein both parties agree that it should be done but disagree about who has the responsibility for seeing that it is carried out. Since, as the agreement on inclusion demonstrates, we are dealing with commonly accepted behaviors toward hyperkinetic children, the substantially lower percentages relative to dominance and legitimacy are important. Had we chosen role items which were more controversial, more esoteric, then the disagreements relative to dominance and legitimacy could be explained either as an artifact of the novelty of the items or the triviality of the items. They would be academic since they would be expectations about behaviors unlikely to be engaged in or remote from the reality of the diagnosis and treatment of the hyperkinetic child. What we believe these data show is the inability of individuals who are charged with the responsibility for the delivery of services to children to develop the working agreements necessary to provide a cohesive and rationalized approach to the delivery of those services.

What other data from our research show (and time and space preclude their presentation) are the individual role responses of the participants. In this analysis, we focused on the beliefs of parents, teachers and physicians about who should be dominant and legitimate in the various role behaviors. Although data in Table One indicate similar patterns of agreement among the three dyads, other analyses indicate that each of the samples - parents, teachers and physicians, tend to have different feelings about who should be dominant and who legitimate in the role behavior. The data indicate that parents and physicians each tend to nominate themselves as legitimate and dominant. A tug of war for legitimacy and dominance is evident between the parents and the physicians. Both parents and physicians see the teacher as rarely dominant and often not legitimate, and teachers concur. Teachers also tend to agree with the parents in their definition of who should be dominant and who should be legitimate.

Physicians, who have great power, do seem to be "odd man out." This is certainly more debilitating to coherent action in social systems organization than if, for example, the teachers, who have least salience in the situation, differed significantly from the parents and/or the physicians. These data, in our analysis, indicate extremely strong incoherence because of the nature of the responses of these competing adults.

A good test of the usefulness of our approach is its application to the question: How can we understand the failures, difficulties and problems that are enountered in the diagnosis and treatment of hyperkinesis? If one uses the medical model conceiving of hyperkinesis as an organic pathology and of the treatment as a response to that pathology falling within the exclusive realm of physicians, there is the liklihood that the problems that are encountered are seen as random and idiosyncratic, uncontrollable and only marginally the responsibility of the treating physician. Teachers, parents or physicians who view the situation in this way will tend to explain the difficulties as the consequences of a "crazy teacher," an "uncooperative parent" or an "incompetent physician."

Using our approach, these problems constitute predictable consequences of the nature of the structure of roles in involved systems. It makes better sense to create and apply a perspective in which these "intruding idiosyncrasies" become conceptualized as properties in the system of explanation and treatment.

Of course, the issue that is uppermost in the minds of many who are concerned with the diagnosis and treatment of hyperkinesis is the resolution of these problems. We believe that the approach we have taken is useful for several reasons.

We have argued that it provides more complete explanatory power than does a model confined to the medical system. There is another reason. From our framework, it is possible to remove many of the attributions of blame and guilt which we believe compound the problems of achieving a solution. Those of us who are concerned about finding ways to increase communication recognize that we cannot get physicians to incorporate educational factors by castigating them for their arrogance and rigidity. What this perspective does is substitute the notion of inadequacy for the notion of evil. Explanations of calousness, laziness, evil and the like are not required to understand the difficulty besetting our ability to deal with hyperkinesis.

Along these lines, a word of advice: Those who seek to write compelling muckracking books and articles about the situation are best advised to not do as we have done, to not sit down and talk at length with the involved persons. When one does this, it becomes more difficult to see villains. One is more impressed by the general desire on the part of all parties to do a decent job and to do what is right for the child, even though one sees shortcomings, errors, mistakes and problems. Both data and interviews are much more likely to uncover dedicated, if flawed, saviors.

The approach that we have taken has another important consequence. It equips us with concepts that are helpful in implementing suggestions found in the literature. This is best illustrated by the often cited recommendations by physicians and educators about the need to make a place for parents and teachers in diagnosing and treating hyperkinetic children. If one is oblivious to the structural problems which are responsible for generating problems, then one tends to feel that one can "say a place" for these other participants. We indicate that participation is desired and welcomed and expect that participation will follow. It seems clear that it is not until one understands the full meaning of the word "make" in the expression "make a place" that the needed collaboration can occur.

To "make a place" for participants in caring for hyperkinetic children means to create those social structures, within medical practices, schools, families and other caretaking organizations, that make participation necessary rather than permissible. It means that the educational plans for the hyperkinetic child are defined as incomplete until the physician's contribution is incorporated. It means that we act on our belief that information from school personnel and parents is essential in understanding the child's problems and solving them. It means that roles of the significant persons in each system are formed to accept and integrate knowledge and information from those in other systems. It means that there is a single integrated support system for the child.

If we view the events that have transpired over the past several years with regard to the treatment of hyperkinetic children as isolated incidents, then the creation of solutions is valuable only to insure that children being treated currently, and those who may be treated for hyperkinesis in the future, will be assured of the best that can be done for them. Reflection on our data leads us to believe that - even with the limits in technical knowledge, we are not treating the hyperkinetic children as well as we could. We believe that additional and more potent psychopharmacological techniques for children and adolescents will be developed. When one recognizes that psychopharmacological technology has not reached its culmination with the development of this generation of existing drugs, one sees that our need to think carefully and to create the social forms needed to apply to this technology sensibly is well worth the effort.

Table 1

Agreement Among Dyads of Parents, Teachers and Physicians About Behaviors Toward the Hyperkinetic Child

	Parent/Teacher Dyad Agreement		Parent/Physician Dyad Agreement		Teacher/Physician Dyad Agreement	
Role Dimension	f	%	f	%	f	%
Inclusion of proposed behavior in regimen of child (INCLUSION)	2580	85.26	3542	85.23	2102	85.18
Specification of person responsible for proposed behavior (DOMINANCE)	1014	41.19	1377	41.85	732	37.18
Specification of persons legitimate to be involved in proposed behavior (LEGITIMACY)	332	21.63	391	18.70	221	18.00