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Informed Consent in Child Psychiatry – A Theoretical Review

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ABSTRACT

In this theoretical review we examine the issue of informed consent in child psychiatry. We describe the development of the concept of informed consent in the history of medicine and review the limited research on its application in child psychiatry. We analyze special features of informed consent unique to our field, such as the capacity of the child to give consent, the status of the "mature minor", the special situation of the child within the family, the place of informed consent in psychotherapy, and the ability of child psychiatrists to give full information prior to consent. We conclude that children, even under the legal age, should be part of the process of giving consent to treatment. On the other hand the complex process of obtaining consent should be aimed at achieving real involvement of patients and families and not merely adhering to formal requirements.

Introduction- The History of Informed Consent in Medicine

Some 3500 years ago, the Hebrews, made their exodus from Egypt. When God gave them the Torah, they said: "We will do and (then) we will understand". This was probably one of the first instances of consent where no claim was made for information. Since then for many years, individuals and societies blindly followed prophets, Gurus, leaders and accepted everything they suggested, including death. They did this with no demand for any information. They followed their belief. The history of medicine reveals how physicians were similarly treated in ways that were usually reserved for gods.

The basic principles of Hippocratic medicine were beneficence and paternalism and they were dominant in the practice of medicine throughout the medieval time and late into the early modern times (for review see Faden and Beauchamp, 1986). This meant that withholding information from patients was considered justified if it served the interest of the treatment. This practice is reflected in other times and cultures. For example, both physicians and religious leaders were called "wise" (H'akim) in the Arabic language. The use of Latin to communicate and describe diseases added to this linkage with religion and God. Physicians had the power to save from death and by doing so were competing with God. If by fear or by respect people did not ask them for any information but only for reassurance and support in their lives. It is not surprising that physicians used and abused this power.

Starting in the 19th century a progressive and steady move towards appreciating the telling of truth to patients as a value became apparent. Still deep into the 20th century there was a tendency of physicians to prefer a paternalistic approach towards patients over respect of their right for autonomy (Katz, 1984). This was even more so in the field of medical research. Until the middle of the 1950's research in medicine was sparse, intuitive and heroic. Pioneering researchers took for granted their own justification and contribution for human kind and therefore felt no need to ask for consent. For practical reasons researchers used as subjects prisoners, the mentally retarded of all ages and orphans. After World War II, the world was outraged by the murders carried out in the name of science by Nazi physicians. In the Nuremberg Code, the judgment by the war crimes tribunal at Nuremberg, were laid down standards to which physicians must conform when carrying out experiments on human subjects. Among them was specific address to principals of informed consent: "Ethical practice requires the investigator to inform the participant of all features of the research…. Openness and honesty are essential characteristics of the relationship between investigator and research participant…Ethical research practice requires the investigator to respect the individual's freedom to decline to participate…or discontinue… " (Nuremberg Code, 1948-1949). This was followed by other major international declarations such as the Helsinki Accord in 1964 and the UN Convention of the Rights of the Child in1989.

Although initially addressing research, these basic principles of the Nuremberg Code are now accepted as the basic moral ethical and legal concepts of all aspects of medical practice: among

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them, and first of, the voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent and should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit or duress, and with full information regarding the issue at hand.

Still, the implementation of these principles to daily clinical work is far from satisfying. Harth and Thong (1995) found that parents did not understand many of the details of the informed consent they gave for their children to participate in a clinical trial. Many times, doctors do not fully discuss risks and benefits of treatment and do not make sure that their patients understand them. When patients have access to more information they make different decisions regarding the proposed treatments (for review see Deyo and Patrick, 2005).

Mentally ill patients found their place among other sick persons only relatively recently, some 150 years ago. Considered as possessed persons, cursed by God, scary and threatening, they did not deserve any consideration as medical patients, let alone treatment, until the implementation of moral treatment to psychiatric patients by Pinel, at the end of the 18th century. The shift from paternalism to respect of autonomy in psychiatry was even slower than in other fields of medicine. Considered as unable to have access to any normal communication and understanding, the best doctors thought they could do for them, was to impose their care, and even force them to receive this caring treatment. The new awareness for patients' rights is reflected in more recently formulated laws for mentally ill persons in different countries, which limit considerably psychiatrists' power to make unilateral decisions for their patients.

Informed Consent in Child Psychiatry

The ethical dilemma of paternalism or beneficence vs. autonomy is much more pronounced in the treatment of children with psychiatric disorders. Children were always thought of as inseparable from and dependent upon their parents. Having a psychiatric disorder makes them much more so. Although lengthily detailed in various modern charters and documents, children's right for autonomy, according to their emerging capacities, is far from being fulfilled, even in developed countries. There are no studies on the implementation of recommendations and laws regarding informed consent in child psychiatry. In our experience clinical practices vary from real efforts to explain to the child in her own words about the procedure, treatment or research to be conducted, to merely "lip service".

Child psychiatrists and psychotherapists, less frequently discuss the sphere of medical ethics. Jurists, in collaboration with developmental psychologists, have made the most important contributions in this field. The study of consent depends in large measure upon the social contexts in which medicine is practiced, and on the laws in force in different countries. The stress placed on certain aspects of consent (age limits for example) clearly depends on the criteria governing the laws applicable in each country. For years the legal systems in many countries considered that children and adolescents were incapable of making important decisions concerning their life including the management of their health. A discrepancy exists between the different rights granted to minors. Thus, in many countries the courts have been more explicit and liberal when determining the rights of minors in criminal or penal cases, granting them rights and capacities of which they were deprived in the field of health. However, in the last decades, rights have been regularly granted to minors in certain fields of health management such as contraception and abortion, and also access to psychological treatments (Schowalter, 1978, Guyer et al. 1982, Potter and Evans, 2004). Thus, the participation of the child in decisions which concern him /her should be encouraged and developed for ethical and for legal reasons.

The Ability of the Child to Give Consent

Studies of children's ability to consent are many times based on the work of Piaget and his successors, with the aim of establishing chronological norms of cognitive, and to a lesser degree emotional, development (Green and Stewart, 1987) . The stress placed on chronological indications is all the more marked since the criterion of age has been one of the most commonly accepted in many countries. For centuries, age has played an important role as a necessary guide for fixing the important stages in a child's place within the community and in the modification of his/her role. But in regard to the needs and expectations of children and adolescents, different countries have used these chronological guides in very different ways. In terms of consent the relevant Piagetian key stages are the passage from pre-operational thought to concrete operations towards 7-8 years, and the development of formal thought between 11 and 13. Experimental studies carried out to determine the competence of minors regarding consent are very few. They are based on the principle that the child is capable of 'consenting' if s/he is able to grasp the nature, importance and possible consequences of the treatments or investigations suggested. The results of these studies bring to the fore the early capacities of children to take decisions concerning their treatment.

Weithorn and Campbell (1982), administered to 96 children and adolescents a measure developed to assess competency according to 4 legal standards. Their findings confirmed that access to formal thought was necessary for a subject to be able to consent. While minors of 14 years of age had a degree of competence identical to that of adults, children of 9 had lesser understanding of the difficulties of taking into account the various factors involved in the choice they are being asked to make. However, they were found to be capable of expressing, like adults, their preferences concerning treatments, and of participating actively in decisions. Susman et al. (1992) and Dorn et al. (1995) found that knowledge of children about their participation in a medical research protocol was related to emotional factors of anxiety and feeling of control more than to age and cognitive development. That is the reason Laor (1994) suggested that no distinction would be made by age but by evaluation of competency for all ages.

Scherer and Reppuci (1988) found that a minor in a situation of consent, faced with social and normative pressures, may respond

by making a show either of conformity or of compliance, but also of "reactance," which is a form of anti-submission. In their study adolescents responded to parental influence. Parents' pressure had the effect of weakening their decision about the choice of treatment that they prefer. They did not tend to oppose their parents systematically, because of the severity of parental reactions, or because the decision about their treatment lacked importance in their eyes. The gravity of these decisions regarding the treatment was a major factor that affected the adolescent's response to parental influence: the more important the consequences and implications of the treatment, the less the adolescent submitted to parental influence. The modalities of their decisions were not different for psychiatric treatment.

More recently, Billick et al. (1998, 2001) demonstrated again that competence to give consent in pediatric patients was correlated with age and measures of intelligence. No correlation was found with psychopathology.

The results of such studies encourage clinicians to treat even their youngest patients as active partners in decisions concerning their health. For some, the respect of the child's rights and autonomy prevails, for others it is a matter of encouraging compliance with the treatment. But to what extent do children and adolescents who are capable of discernment wish to exercise their rights? The answer to this question is undoubtedly linked to sociological as to individual factors. The position of the child and adolescent psychiatrist enables him/her to estimate and analyze the intrapsychic and interpersonal dynamics that underlie these situations. These issues have to be addressed by formal research.

Working with Parents and Families

Studies of the child's consent must be considered in relation to the status of the child within the family. Recognition that the interests of parents and children are not always the same (this is obvious in cases of abuse or neglect) must lead to greater attention being paid to the child's opinions. The contract which links therapist and parents is accompanied by the therapist's moral contract with the child, whose interests and rights must be defended. As in any other medical disciplines where treatment is given to children, therapeutic measures in the field of mental health cannot be applied without the consent of the parents or legal guardians. The therapist must be sure that the parents are capable of meeting the requirements of free consent. The only situations in which treatments can be administered to a child without obtaining consent from the parents are rare urgent medical situations or crisis situations.

It is good clinical practice to be respectful and non-judgmental when approaching the parents of mentally ill children's. But to what extent does the child psychiatrist fulfill his/her duty to inform the parents? Though in various countries, the scope of the duty to inform is more or less defined by legal texts, it seems to us that in our social context at least, a considerable degree of reserve is often maintained regarding certain aspects of the information involved. Many parents are not informed of the precise diagnosis of their child. Some therapists fear the negative effects such information may have on the parents' image of their child, particularly when grave diagnoses are structurally conceptualized (for example, childhood psychoses). Others stress the difficulty of giving information whose value sometimes seems of limited significance. Such reticence seeks to protect the patient or his entourage, but there is no doubt that it is not always justified, and may even be contrary to the expectations of most parents. Many times, this reticence is merely another manifestation of the frequently ill-founded fear that the announcement of a diagnosis has regrettable repercussions on the patient.

The dissatisfaction of our patients' parents often arises from the limited nature of the information they are given about the modalities of treatment and the treatment's results. The limitations imposed at present on research on the results of many forms of treatment pose ethical problems, and must incite us to prudence regarding the value of information given to parents about the benefits to be expected from certain treatments. This aspect of information plays a fundamental role in obtaining real consent. The information parents want is not always the information we can or want to give them. It is not always relevant in our eyes or they may be searching for specific information that supports their beliefs or their position. Their consent is never easily achieved but is the result of a consistent and positive discussion. Clinicians should also be careful not to take advantage of parents who are in such despair that they are ready to allow complete freedom with their children.

The obtaining of parents' consent must be perceived in a broader context which includes an understanding of the particular dynamics of each family, of the kind of efforts invested in the patient, and of the repercussions of the child's symptoms on the family economy. It is often the outcome of a process, which aims at creating a therapeutic alliance with the parents and the child. Where psychotherapeutic or institutional treatment is recommended, a long preparation is often necessary. During this phase, the clinician also has the opportunity of evaluating parents' possible attitudes towards the freedom of decision they grant their child. For some parents, the considerable powers they allow their young child are the projection of their own childhood desires of omnipotence and, under the guise of liberalism, they translate a difficulty in recognizing the child's need to be accompanied in his choices and decisions. Clearly, in this analysis of the capacity of consent within a family, the clinician asks himself/herself questions about his/her own system of values and about his/her counter-transferential attitudes on this subject.

Working with families involves dealing with conflict of interest as well as their change over time. Refusal of treatment after a period of investigation is one of the most frequent modalities of a breakdown in the relationship. Out of respect for the family's integrity and parents' autonomy (as responsible for their dependent child), it is very rare that steps are taken to defend the interests of the child and her/his right to psychiatric treatment, unless other aspects of the family environment fully justify State intervention. This attitude is dictated by the fear of placing the child in a conflict of loyalty with his/her parents, a conflict that would have regrettable repercussions on the therapeutic process. Many psychotherapists are extremely reticent about undertaking treatments, which are opposed by one of the parents, even when that parent no longer has parental authority. Though the consent of both parents is always desirable, indeed indispensable, the

seeking of this consent in cases of conflict between the parents sometimes obscures the desire and expectations of the child concerning treatment, particularly if s/he is not yet capable of giving full consent. In our view, the child should not be deprived of her/his right to psychotherapeutic treatment providing that the treatment is not an expression of the parental conflict. Further, the framework of the treatment must allow for a clarification, or even an interpretation of the child's conflict in the face of the parents' disagreement.

Informed Consent in Psychotherapy

Psychoanalysis and psychoanalytically oriented psychotherapy are treatments. Whoever conducts such treatment has the lawful obligation to obtain an informed consent for it. The therapist has to explain the patient all advantages and disadvantages, indications, contra-indications and also all alternatives to this treatment. Such an implementation of the law makes any psychoanalysis impossible if accepted at all. There is no way to elaborate on any transference, positive or negative or to elaborate on unconscious motivations among other components of the therapeutic tools. Theoretically that makes every psychoanalyst and psychotherapist overruling the rights of the patients even if practically there is no other way of presenting the treatment to them.

Family therapies give rise to a particular problem because the risks and benefits differ from those of individual therapy. They can produce effects which one member of the family considers undesirable. Sometimes this therapeutic approach is refused, because not all family members wish to participate, or because some the family members feel under pressure. This can upset the balance that exists in the family. Most forms of family therapy (and other psychotherapies as well) employ certain types of manipulation, which limit a "true" informed consent, and the freedom of choice of treatment.

The Mature Minor

The U.S. courts and many State legislatures have evolved the concept of the "mature" or "emancipated" minor (Schowalter, 1978, Guyer et al., 1982), and the same process occurred in other countries such as the UK (Bridge, 1997). This means that certain minors are considered as adults and as such are capable of being informed and would understand the nature and consequences of the medical treatment or procedure in question and thus should be considered as having the capacity and right to give informed consent.

Despite the greater autonomy granted the child, a certain number of problems remain which limit the youngster's access to treatment. The possibility offered to minors capable of giving consent to benefit from psychotherapeutic treatments without their parents' knowledge, does not automatically lead to a greater use of treatment facilities. The lack of information concerning such rights often goes hand in hand with difficulties created by the financial aspects of the treatment contract. We can respect the need for confidentiality of treatment even if parents remain responsible for the financial aspects of such a contract. Confidentiality is a condition of success of treatment and as such is in the parents' interest to be respected. Moreover, this confidentiality gives the child a sense of her/his autonomy and what positive human relations have to offer. Caring parents, who are not competing with their child or afraid by him/her, will profit from this change.

Informed Consent and Research in Child Psychiatry

Within the research framework, the child enjoys very special protections and another important right is granted to her/him, for in general, if s/he is over 7 years of age, her/his assent is officially necessary in addition to the written consent of his parents (Munir and Earls 1992). Children's motivations to participate in research are complex and complicated. Beyond their alleged understanding of the design of the research, children are faced by the advantages and disadvantages to be a research subject. If this research does not have any direct profit for the child (as a control for example) they can be satisfied to serve society in an altruist way. They might enjoy skipping school that day, or receiving some incentives for participating. Researchers and IRB members should judge whether these benefits do not interfere with the neutrality requested in obtaining informed consent

Limitation of Informed Consent

Silverman (1989) considers obtaining informed consent a myth. We share this opinion. If patients or their legal representatives do not understand, or incorrectly understand, or insufficiently understand the implications of clinical research, what can one expect of children or adolescents, especially if they are mentally ill?

The ill person's state of mind is the state of mind of a person threatened by death. As such s/he is totally dependent on the only person who claims to be able to save him/her: the doctor. The state of being ill is regressive by nature. Ill people seek refuge in another's arms, they seek a heart to believe in and feel secure. As such, patients are never absolutely free people and their choice can never be a free choice due to the threats related to their illness and their dependence on their doctors. Doctors apparently choose their profession for these similar reasons: being this person. The ability to exercise complete freedom of choice does not exist, not for healthy human beings and certainly not for the ill person. This occurs all the more so for mentally ill children.

It is impossible to give all relevant information concerning diagnosis, treatment or research. It is inconceivable to answer all questions asked by patients or research subjects. In our field of mental heath it is accepted that we are not obliged to disclose rare side effects. For example neurological changes, hormonal changes and weight gain occur frequently as a consequence of antipsychotic medications. An honest disclosure of all side ef-

fects will lead to refusal or reconsideration of most medication. Recent studies on informed consent reveal that there exists a positive correlation between the amount of information and the amount of detail given to patients, and the rate of refusal or postponement of treatment (Deyo and Patrick, 2005).

Even in its politically correct formulation, there is a flavor of coercion, persuasion, if not manipulation in informed consent as stated by Faden and Beauchamp (1986). People are forced to sign forms that are more useful for the physician than for the patient and certainly the young mentally ill kid. This form is presented to patients when they are in despair and need for any medical help, when they can hardly ask their questions.

Summary

It has become clear that the Nuremberg ethical codes regarding informed consent are, at least in the way that they were worded, just a 'sleight of hand', an illusion, utopia. Better moderate, or humanize the rules than making them impracticable. An impractical or impossible to implement ethical recommendation is unethical in itself. It merely serves as a fig leave and discharges its users without giving real protection and without fulfilling its real purpose.

The history, theories, philosophy, legacy, of informed consent are an expression of ambivalence between two values. Child mental health is the field where this ambivalence comes to its most extreme level. These two conflicting values are: 1) the value of a person's autonomy, self-determination, free will, which means providing complete and comprehensive information to the patient, and 2) the aid the patient receives regarding his sickness, which means, giving the patient the best known treatment even if it involves avoiding her/his opposition to this treatment if s/he knows "too much" about it. That does not imply imposing this treatment against his/her will but it does imply the use of fair information, and thus convincing him/her of the physician's good intention to treat her/him the best s/he can. We respect the patient's right to receive other opinions, including those of non-medical persons, like priests or rabbis or other significant figures in their lives. We will have to compete sometimes with these opinions or accept them if we are sincere enough in our intention and will to treat and help. The patient and her/his advisors cannot have the same quality and quantity of information the medical staff has. It is utopian to share all information in the name of a free and full decision-making process.

It is absolutely ethical to try to convince our patient that our treatment program is the best for her/him if this is done from a position of a caring and sincerity and not for any other interests (that we are conscious of) such as glory, promotion, publication, peers competition, etc. Informed consent, as it is formulated by laws and regulations in many countries is threatened by irrelevance because it is impossible to implement, not only for mentally ill children, not only for children but for all patients. It is a law that can be only transgressed, detoured (consciously or unconsciously), and reduced to a minimum in the avoidance of law suits. This is certainly not in the best interests of the child or of adult patient. Hippocratic paternalism is preferable to hypocritical informed consent. Paternalism is not always a pejorative concept. It is the doctor's answer to a patient's basic will and needs.

Ethics as such is the concern for human relations and is present and can be considered regarding every human encounter. Medical Ethics should be approached in 3 stages:

The first one is to question every procedure: treatment, research, training, administrative decision, in terms of moral values: There is no routine, nothing is evident, and no automatism can be endorsed. This questioning leads to the second step: *formulating the ethical dilemma.* This is a dilemma between values, two or more good, acceptable and moral possible solutions to the problem. These values can be freedom of human beings, self-determination, respect of autonomy and commitment, among others. *The third step* is not less important, though perhaps more often forgotten. *It is the choice of one, unique possible solution among others and action according to this decision.* The answer to the ethical dilemma has to be given by the person, physician or other, in direct charge of this specific patient. Even if advised by ethicists or a council, or an IRB the final decision is his or her own decision and s/he has to endorse it. Too many discussions on Ethics conclude with a question mark. The ethical attitude is an operative one. These decisions are based on knowledge, experience, counseling and staff discussions and no less on physicians own values rooted in their education received from their family, their community and in their school of medicine. Ethics can be taught but it is more than just knowledge. Doctors can be trained to take ethical decisions through their contacts with teachers and peers, by participating actively in elaboration of ethical dilemmas and their solutions, by imitating the moral attitude of their seniors.

The late Donald Cohen taught us that it is better to get to know your doctor than to try to know what he knows. Reliability is of greater value than having an illusion of knowledge. He taught us that informed consent, as a powerful principle, cannot be implemented except when taking into consideration people's needs and sensitivities. It has to be more than anything else an **involved consent.**

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