

Between the psychiatric diagnosis and the “family diagnosis”

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Summary

If the idea of the bio-psycho-social model is not to be merely a concept on paper, the family dimension must be taken into account in every clinical diagnosis and concept of treatment. The example of schizophrenia illustrates the advantages and problems this entails.

Accommodation of the family context has clear benefits: it enables a more thorough understanding of the patient and creates the foundation for action to reduce the risk of relapse. It is therefore strange and worthy of reflection that despite the effectiveness of psychoeducation, it is not a part of the canon of treatment: on the one hand families are not always invited to co-operate, and on the other they often refuse the offer of co-operation themselves. In this situation the relationship between the psychiatrist and the patient's family needs analysing, in particular their mutual – and often subconscious – emotions and prejudices, for these can create the beginnings of a dysfunctional “vicious circle” and cause the entrenchment on both sides of attitudes preventing the conclusion of a therapy contract.

How to break this impasse and help to create a positive team? Paradoxically, the potential for therapy is greater when – especially at the start of the treatment process – the psychiatrist is “capable of not knowing” and is prepared to listen to the perspective of the members of the patient's family without prejudice and to take a close interest in the “family's story”. Only once the psychiatrist has heard and accepted the family's perspective can they deconstruct the elements of the “family's story” that contribute to the problem together and both seek changes for the better.

Unlikely as it may seem, this may prove a considerable challenge to the psychiatrist, who is accustomed to controlling the therapeutic situation through his psychiatric theory and diagnosis, his psychiatric language and his psychiatric institution.

The above issue is part of a more universal dilemma: how far does the psychiatrist's “linguistic power” extend and when is it beneficial to that therapy to share that power with the patient and his family?

Key words: psychiatric diagnosis, family context

Introductory remarks

The words below discuss how important and – strange as it may seem – how hard and not necessarily obvious it is to work with the family of a psychiatric patient. I will attempt to prove the thesis that a major source of problems in co-operating with the family of a schizophrenia patient is the psychiatrist's attachment to his¹ own perspective and his insufficient sensitivity to the language and perspective of the family.

The bio-psycho-social model: theory and practice

On the theoretical level there is no doubt. In 1965 the World Health Organization published a document entitled “Aspects of family mental health in Europe”, in the introduction to which the authors write: “... [T]he study of mental disorders began as the study of individuals, and only gradually did it become the study of individuals in the social environment. As a result of this approach, it has become increasingly apparent that the mental health – or ill health – of each member of a family is inextricably bound up with that of other members, influencing it and being influenced by it both favourably and unfavourably.” [after: 1, p. ix]

It would be hard to find a psychiatrist who – in theoretical discourse – would question these words and claim that co-operation with the family, whether in the form of psychoeducation or therapy, or at the very least face-to-face talks, is unnecessary or harmful.

And yet an examination of day-to-day practice proves that such co-operation does raise doubts and is far from being as obvious as the WHO declaration of almost 40 years ago suggests.² Why is it that the theory is so far removed from the practice? The list of factors is long. The emphasis in both pre- and post-graduate education is on the biological dimension of psychiatry. The spectacular effects of pharmacotherapy in treating psychoses have marginalised the social and family context of illness and treatment in the minds of many psychiatrists. The approach is that working with the family is “...important, of course, but not the main priority, after all”, and in the volume of their professional duties they leave matters relating to the patient's family to people specially trained in such areas. And as family therapists are few and far between, the family context in the treatment of schizophrenia is often overlooked. These are the costs – costs which I hope are avoidable – of specialisation within the field of psychiatry. For the link between the situation of the patient's family and the success or failure of therapy in schizophrenia is evident enough to merit attention.

It is therefore advisable to look at the family context in schizophrenia.

The family context

The interdependencies between the family and schizophrenia can be approached

¹ Read “his/her”.

² Reference is made here only to the “family context”, but the issue is wider and covers the whole of psychiatry.

from several perspectives. A relatively popular thesis, although one that is no longer as strong as some years ago, is that of the influence of the family (relations within the family, communication, parental attitudes) on the genesis of schizophrenia. Most commonly cited here are Frieda Fromm-Reichman’s concept of the schizophrenogenic mother [2], Murray Bowen’s three-generational model of the origin of schizophrenia [3], the double bind of Gregory Bateson and his Palo Alto group [4], and newer hypotheses including Mara Selvini Palazzoli’s theory of family games that lead to psychosis [5].

At present, pathology within the family is treated not so much as a cause of schizophrenia but as a mechanism that sustains the dysfunction of an individual. In this context the most respected theory is the Expressed Emotion Theory, which has been being refined for over 40 years, and which assumes that the risk of relapse depends on the attitudes of family members towards the sufferer [e.g. 6, 7]. In families characterised by a calm benevolence towards the patient the risk of relapse is several times lower than in those where even one relative is excessively emotionally or critically disposed towards the patient. Particularly attractive to the clinician are the results of research in Finland, which suggest that the strongest predictor of a positive outlook over a five-year period is the presence in the family of at least one empathetic person [8].

Another current is the view of the patient’s relatives as those who bear the burden of the illness. Descriptions of this burden can be found chiefly, although not exclusively, in the publications of family support organisations such as the National Alliance for Mentally Ill. Research that focuses on defining the difficulties faced by families indicates that this is often a burden that leads to their disintegration. For instance, research by a body known as the Scottish Group [after 9] revealed that over three-quarters of carers are, in the light of its *General Health Questionnaire*, classified as *psychiatric cases*. Although the results of other analyses are not so dramatic, there is nevertheless no doubt that the illness of one of its members takes a vast toll, not only in emotional terms, on the family as a whole.

And lastly, an approach more complicated from the angle of research methodology, but the one that best reflects reality, is the consideration of the mutual and circular relationships between the family and the sufferer. This systemic perspective takes a neutral stance in debates on aetiology, instead attempting to analyse interdependencies and the processual and reversible nature of phenomena. This angle is characterised by the least reductionist approach among researchers (either those with a tendency to reduce phenomena to their biological dimension or those who underestimate the importance of the biological aspect and focus on the interpersonal dimension alone).

In summary, today the profession is increasingly departing from a unidirectional perception of relationships, which benefits an all-round description of the case: it nowadays perceives not only the influence of the family on the illness but also the impact of the illness on the family. The relationships between the family and the sufferer are interpreted with the awareness of circular causality.

The psychiatric diagnosis

As psychiatrists seeking the truth, we seek – for understandable reasons – “an objective truth”. We hope that clinical analysis, based on our knowledge and experience, and, where necessary, that of those more experienced than ourselves, will lead us to the truth, for the goodness of the patient.

The hope of arrival at an objective truth is bolstered and justified by progress in natural science, which is visible – in psychiatry, for instance – in the advancement of knowledge of the construction and functioning of the brain. Achievements in pharmacotherapy and increasingly sophisticated diagnostic systems strengthen these hopes still further.

And yet doubts still arise. I bring them up not to question the obvious progress in psychiatry but to draw attention to some of the pitfalls to which the psychiatrist is prey, in particular the psychiatrist who is confident of his knowledge and its objective veracity.

By way of introduction I will cite an experiment which is not fully appreciated. It was conducted more than 30 years ago by the then young psychologist David Rosenhan [10].

In its simplest terms, this experiment can be summarised as follows. Eight of Rosenhan’s co-workers went to different psychiatric hospitals simulating mental illness. The only expression of this simulation was the untrue statement that they were “hearing a hollow noise”. Other than that, the “fakers” looked, behaved and talked entirely normally. Nevertheless, in each of the eight cases the psychiatrists not only diagnosed psychosis and hospitalised their apparent patients, but also embarked on treatment at once, although already the following day the participants in the experiment announced – as had been arranged in advance – that “the voices had stopped”. The debate on the outcome of this once much-publicised experiment took place in the early 1970’s, at a time when the tension surrounding antipsychiatric ideas made calm reflection difficult. Today, with over 30 years’ hindsight, it is worth taking another look at David Rosenhan’s experiment.

In my opinion, the groundless hospitalisation and treatment was not due solely to the incompetence of the psychiatrists. Irrespective of Rosenhan’s intention to ridicule or compromise psychiatry and its diagnosis (as some interpreted it), to my mind, an important conclusion that can be drawn from his experiment is a demonstration of the importance of the epistemological framework. In other words: if we look at a situation from a previously assumed perspective, then we will see what that perspective suggests. Language shapes the image we perceive. As in the popular adage that states that if you are holding a hammer you will see nails, so it is with the psychiatrist: if you assume the psychiatric perspective, you will see a psychiatric pathology. And so there is no reason to interpret the actions of those psychiatrists and their haste in commencing psychiatric treatment as ignorance, and psychiatry need not be treated as a bad cookbook containing simple, yet groundless recipes for procedure. When the psychiatrist came into contact with someone who defined themselves as a psychiatric patient, he was in thrall to his language, his discourse, his description. In effect it was the language of psychiatry – with the assistance of people fluent in that language – that constructed the reality of that language: psychiatric patients.

The above example illustrates an important aspect of our diagnosis, and one that is not always fully appreciated: that diagnostic procedures are social constructs. They have their roots in a singular perspective and a singular language. They do not describe reality directly, they only reflect our – psychiatrists’ – way of talking about it. Unaware of this, we are party to a psychiatric game of language, as Klaus Deissler expressed it [11] a key aim of which is to gain control of the situation.

At the same time, there are also many studies that indicate that the effects of our diagnostic procedure are subject to many factors that certainly have no connection with the merits of the case. It has been proven, for instance, that, given the same psychopathological characteristics, it is easier to diagnose schizophrenia in a black patient than in a white one, in a patient from a public hospital than in one from a private clinic, in a lower-class patient than a middle-class one. Psychiatrists have “milder” diagnoses and lower dosages of neuroleptics for rich, white representatives of the middle class [12]. And yet none of this is deliberate.

If, then, our diagnostic procedures are so deeply immersed in our language – which is, after all, a convention – and since the results of these procedures are so greatly conditioned by social, economic and racial criteria (by cultural criteria in general), then the conviction that our knowledge has the virtue of objectivity is unjustified. Our knowledge is merely a reflection of the prevailing linguistic custom (in a given time, in a given place, in a given society). Using the categories of social constructionists we could say that our descriptions are part of the dominant discourse.

And if that is the case, then it would seem sensible to examine just what the ramifications of the cultural conditioning of the diagnostic process are in the context of the patient’s family.

The cultural conditioning of diagnosis

On the basis of our psychiatric knowledge, and making use of it, we can help our patients: tackle symptoms, relieve suffering, ease rehabilitation into society and improve self-control. Our psychiatric linguistic convention also enables us to communicate with other psychiatrists. We can gain satisfaction from our own actions. We can also gain satisfaction from the power that this language and the means to use it gives us. I do not mean “power” in the superficial sense (although this form of power is not alien to psychiatrists). Also worthy of note is “linguistic power”, which defines the way we describe reality. “It is the way I see it. My language denotes the reality.”

It should be emphasised at this point that these words do not suggest doubt in the usefulness of psychiatry or the good that ensues from what the psychiatrist does. They are merely intended to stress that the psychiatrist is subject to a certain convention, which in many respects is useful. The problems arise when he forgets that he is thinking and acting within this convention, and mistakes the accepted convention for objective reality, lending the construct attributes of real life. By blurring the distinctions between convention and reality he risks dismissing other conventions as unimportant or less important, or, which is worse, ceasing to notice them at all, or dismissing them as fictitious. This is the danger when a psychiatrist has to become involved with a family, and his epistemological framework becomes his cage (often so subtly as to be barely perceptible).

For there are fundamental differences between the psychiatrist's perspective and that of the patient's family. Let us take a look at the perspective of the family of a patient who is showing symptoms of psychosis.

"The family diagnosis"

The use of the term "family diagnosis" here is intentional, in order to emphasise that it is parallel to and bears many analogies to the psychiatric diagnosis. The family has its own story about the sick person, its own definition of the problem, and some conception of how the situation will unfold. Below are certain characteristics of that story, that singular "family diagnosis".

Aetiology – or guilt. Lyman Wynne et al. [13] draw attention to the fact that the word "aetiology" is derived from the Greek *aitia*, which means not only "cause", but also "responsibility" and "guilt". This is precisely the case with regard to the search for an aetiology by the family. Of the six most common causes listed by Wynne – supernatural causes, physical and biological causes, unconscious external processes affecting the self, social processes, traumatic life events and processes within the family system – it is these latter that tend to suggest themselves to family members most often. The dramatic "Why?" is shot through with the hunt for the guilty party. Where the psychiatrist looks for objective causes, therefore, the family is embroiled in an intensive, stressful, painful search for the culprit, characterised by a suppressed sense of guilt and fear.

The diagnosis – or the sentence. There is no overestimating the drama of the moment when for the first time in his life the patient comes to a psychiatric hospital for treatment. If we assume, after narrative theory, that people think of themselves and others in terms of a story, then hospitalisation is a sudden twist in the plot. It represents a loss: the loss of the previous – more or less optimistic – vision. The person nominated by the society's culture as the nomenclator (in this case the psychiatrist) bestows a new title on the family saga, one that is diametrically different from whatever it was previously called: "Schizophrenia". This new perspective may or may not be accepted by the family [13], but the power of medical discourse is such that any delay in accepting the new definition of the problem is slight. The moment of definition of the problem as an illness is, in Bateson's terminology, a punctuation in the endless stream of events. The significance of that moment is due to the fact that it not only heralds the opening of a "new chapter" in the narrative, but also sets in motion the search that is fundamentally "a search for causes and a culprit".

The prognosis – or despair. Probably no other aspect of the family map is as charged with emotion as thinking about the future. The vision of the future is coloured by impotence, and by the seesaw between abject pessimism and massive rejection, fear and chaos. This situation, which for the psychiatrist is just another professional task (and which may worry him to a greater or lesser extent), is for the family possibly the most dramatic moment in their lives so far. "And then I thought to myself that it would have been better if he had never been born." This statement, the words of one mother describing the moment she learned that her son had schizophrenia, illustrates

the tension that the family experiences. The family prognosis is more one of despair than of discernment.

The therapy – or chaos. For the family, the hospitalisation and psychiatric treatment may prove a source of additional fear, shame, guilt and impotence, especially during the initial stage. The patient’s progress on the psychopathological scale may not translate into change that is discernible to the parents or spouse. Furthermore, if the therapy is taking place in a department with an ambitious psycho- and sociotherapy programme, it may be the case that sooner or later their loved one develops a good relationship with his therapist, but becomes ever bolder in formulating accusations levelled at his family. Is this a sign of recovery that should be welcomed? And what to make of the fact that consecutive weekend releases aggravate the symptoms? And if intensive treatment with neuroleptics causes the patient difficulties in keeping up a conversation, will that pass, or is this how it will always be? And if after a few months of trying several different drugs there is no improvement, is this how it will always be? And if the psychiatrist tries to comfort the parents (hastily, in the corridor) that “everything will be fine”, but the parents find out that there are patients on the same ward who are in hospital for the tenth or twentieth time, then what does it mean that “everything will be fine”? And if the psychiatrist tells them that their son or daughter is suffering from an incurable disease, whose aetiology is unknown, but whose name is known, and that name is “schizophrenia”, then does that mean that there is any point in treatment or not? And if the doctor says that they have a number of good drugs in the department, but that a very good drug that would have to be imported from abroad and does not cause side effects is very expensive, then who will import it?

It is hard to deny, then, that from the perspective of the family the treatment of the patient may sometimes be accompanied by chaos.

Let us now look at some factors that contribute to the context of the therapy and arise at the point where the perspectives meet.

Where three stories meet

A change in language – a change in responsibility. As indicated above, hospitalisation on a psychiatric ward brings with it a twist in the plot of the family’s story. The language changes. The old terms (e.g. lost in thought, playing the fool, suspicious) are replaced with new ones (e.g. autistic, hebephrenic, delusional). New key words appear, with a military ring about them: leave, debriefing, department, duty.

The responsibility is shifted onto the psychiatrists. Now they usher in a new order, by lending new meaning to the sufferer’s behaviour and words.

The family story is

- psychiatrised (that which was previously inappropriate behaviour is now identified as a symptom of mental illness),
- medicalised (it is now doctors who are responsible for solving the problem, and not the patient himself or his family) and
- institutionalised (the problem is to be solved not at home or within the family, but in an institution).

The relief that the family may feel at the assumption of responsibility by a psychiatric institution may have dangerous consequences in the long term: it may cause the family to lose its sense of influence and causation. In this context (stress and the feeling of a loss of influence on the situation) the family is particularly vulnerable to psychosomatic and depressive reactions, and to the disruption of the family system.

The question therefore arises as to what should happen in order for the family to recover – at least partly – its sense of usefulness?

The illness “organises” the family. In order to avoid disruption it is often the case that the illness paradoxically proves useful. The threatened family system consolidates around this “cause”, and other matters are pushed to one side. The family devote their thoughts, their time and their actions to the illness of their loved one. As family therapists express it (albeit in relation to another disorder, but the phenomenon itself is universal), the illness may become “a central organising principle” [14]. To take these concepts further, therefore, it is possible to distinguish “schizophrenic families”, i.e. those in which the illness becomes the axis around which family life revolves, and “families in which someone has schizophrenia”. “Revolving around the illness” may temporarily help the family through the most difficult times and ameliorate the chaos, but in the long term it intensifies the illness and weakens the family. What is worse, it may hinder or even render impossible the empathetic attitude that the patient so needs at this time. And if the psychiatrist perceives the patient’s relatives to be excessively involved or critical, he gets irritated with them and – directly or indirectly – accuses them of such an attitude. This counter-transference – euphemistically speaking – dynamises the impotence and chaos in the family.

How, in this situation, to ensure that over-involvement and criticism are absent? How to prevent the trap that the illness sets for the family? And how to resist the temptation oneself, to cast critical eyes on the family and become too emotionally involved with the patient?

The stories collide

And so it is that in the psychiatrist’s office the three plots collide: the patient’s, the family’s and the psychiatrist’s. The point of departure is the patient’s story, which is an expression of his sense of disintegration.

The family’s story is dominated by fear, a sense of guilt, chaos, and impotence.

In the psychiatrist’s story the key words include relapse, remission, negative symptoms and positive symptoms (an aside: families have particular difficulty comprehending the concept of “positive symptoms”). For certain reasons psychiatrists also refer to Latin names such as “*Morbus Bleuleri*”. This medical lexicon sometimes also includes terms defining the family: “overprotective”, “pseudo-mutuality” etc.

How these three languages and perspective differ from each other!

And although the psychiatrist’s language may be based on competence, knowledge and experience (and unfortunately sometimes also on routine, distance and burnout), nevertheless this difference in perspectives can generate the “syndrome of three autisms”, to use the ironic term coined by one of my colleagues regarding the relationships between the patient, the family and the psychiatrist. For – this may sound banal,

but at this point it is of central importance – if the three languages are too far removed from each other, too alien to each other, then communication becomes hampered, and sometimes impossible [15].

How, then, to help the family, to give it a sense of agency, to prevent it from becoming bound up in the illness, to persuade it to maintain a calm benevolence towards the patient? And all this in a situation where the family is dominated by this sense of guilt, despair, the threat of disintegration, chaos and fear of the future.

Practical remarks

Although my task was only to describe the problem, and not to offer concrete solutions, it would be illogical not to end by outlining a few practical conclusions. Here they are.

1. The psychiatrist should not ignore the family perspective, if for no other reason than the impact of the family on the progress of treatment and the burden that it has to bear. Clinical experience and empirical research are in accord: lack of co-operation with the family represents the loss of the main ally in the treatment of the patient.

2. The chance to understand and help the family is dependent upon the psychiatrist's readiness to open up to the family's perspective without judging it, subjecting it to a reductionist diagnosis or making rushed attempts to change it.

3. One format that may enable the psychiatrist to discover the family's needs and learn to translate its language, experience and perspective attentively is the family consultation [16, 17]. During a family consultation the psychiatrist and the psychologist learn how the family describes its problem, and what limitations the family is restricted by and what potential it has. The task of the consultants is to remain neutral and interested in the family's perspective, without imposing psychiatric language on it as “the only correct form”. This creates the opportunity to motivate the family to co-operate.

4. The method of treatment should not be selected on the basis of the therapist's preferences or the dictates of custom in a given institution, but should be dependent on the family's preferences. Just as the patient should be treated in accordance with his needs, so the form of co-operation with the family should arise as a result of the family's capabilities, needs and willingness [8, 18].

5. There are many ways to help the family: psychoeducation, systemic intervention, systemic therapy. These forms may be employed to achieve various aims:

- to help recreate a sense of agency,
- to ensure that the illness does not become the permanent axis around which the family's life revolves,
- to teach the family how to remain calmly benevolent towards the patient, and
- to aid therapy in a crisis situation, where family life is dominated by guilt, despair, the threat of disintegration, chaos and fear of the future. The selection and pursuit of these tasks only has a chance of success if the patient's family expresses its interest in and consent to it.

6. In light of the above, the conclusion of a contract is of key importance – a therapy contract between the family, the patient and the psychiatrist. The aims of this pact are on the one hand to overcome the illness and on the other to bring about a

therapeutic change in the family.

7. The psychiatrist's language does not lose its importance in this context, but becomes an element of the dialogue rather than a tool of oppression.

Final remarks

1. In the above approach the point of departure is respect for the language of the family's story and not concentration on the family's pathology. This is not synonymous with denial of the existence of this dysfunction within the family of a schizophrenia patient. Dysfunction in the family members, incoherent communication within the family, and disruption of its structures – these phenomena are often present in a patient's family and can generate hypotheses about the impact of the family on the occurrence and persistence of the patient's symptoms. But judging or diagnosing the family in language used to denote family dysfunctions – although it may suggest itself to many psychiatrists – in the long run divides us and the family, and above all distances the family from us, its potential therapists. As such, treating the dysfunction of the family as the starting point for procedure in treatment may paradoxically create a significant barrier to constructive co-operation with the family and a source of failure of the therapy.

In my view, therefore, there are two traps. One danger is the rejection of co-operation with the family "...because it is so dysfunctional that we will never reach agreement with it". The folly of such rejection has been mentioned above.

The second blind alley is one that affects family therapists, and is the commencement of therapy without agreement with the family, without respecting whether or not the family is prepared to undergo such therapy. We often fail to notice that a patient's family does not come to us for treatment. Family therapy is possible and in many instances desirable, but only when the family itself reaches the conclusion that it wants to change and when a therapy contract is concluded. The opening up of the psychiatrist to the family's perspective is a precondition for this.

2. The above theses may appear naive when so many schizophrenics are treated under formal consent, when good co-operation is so difficult, when our psychiatric language is so obviously useful and vital. If we add to this the problem of lack of time, this rejection could be considered justified. Yet only once we surrender our "psychiatric imperialism" can we not only understand and help the family, but also design a construction therapy contract. By avoiding a power game, and enforcing less, we gain more (for the patient and his family). This paradox applies not only to schizophrenia but to all of psychiatry.

3. In recent years the idea of shared decision-making has been developed in medicine, which involves making the treatment process the subject of negotiation between the therapy team and the consumer of medical services [19]. Such a change is particularly important in psychiatry – but also particularly difficult. Until the principle of shared decision-making develops in psychiatry, therefore, we can at least develop

and reinforce the process of respecting the family perspective.

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