Psychiatric worker and family members: pathways towards co-operation networks within psychiatric assistance services

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Abstract

The family's role in patient care was greatly altered by Law 180. This law, introduced in Italy in 1978, led to a gradual phasing out of custodial treatment for psychiatric patients. This different mindset, which views the family as an alternative to institutionalization, leads to it being seen as an essential entity in the setting up of community service dynamics. We interviewed health professionals in order to understand obstacles of collaboration between family members and mental health care workers. The goal was to uncover actions that promote collaboration and help build alliances between families and psychiatric workers. Results showed that health professionals view the family as a therapeutic resource. Despite this view, family members were rarely included in patient treatment. The reasons is: the structures have a theoretical orientation of collaboration with the family but, for nurses not are organized a few meeting spaces with family members. Services should create moments, such as multi-family groups or groups of information, managed by nurses and not only by doctors. These occasions it might facilitate the knowledge between professionals and family members.

Introduction

The history of psychiatry describes the medicalization processes and the mechanisms by which society has emarginated *diversity* and has always been imbued with the attitudes which mental health institutions and services have had towards the patients' families.[1]

The advent of psychotherapy and psychoanalysis was the turning-point when theoretical and clinical medicine was first concerned with etiology of psychiatric disorders. This prompted a redefinition of the role of family and their importance in mental health care.[2] As discussed by Castel spirals of guilt are no longer constructed, the aim nowadays is rather to construct dialogues which support and promote the family as an entity capable of replicating and optimizing modern welfare systems.[3] The role of family members has changed over the centuries, especially since the closing down of lunatic asylums, and this has led to responsibility for the patient being shared between the health service and the family network.

This new scenario questioned the old concept of *delegation to the custody of...*, allegedly the only concrete answer to the family's perpetual oscillation between the need for assistance, the impossibility of a *cure* and the desire to get rid of a problem. Now that the possibility of totally delegating the task of care to the health services is decreasing, the family begins to be defined as a resource for community psychiatric services. This different mindset, which views the family as an alternative to institutionalization, leads to it being seen as an essential entity in the setting up of community service dynamics. It is a new approach which is bound up with new care models and with the changes in the subjects involved.

As discussed by Saraceno there is a change in perspective, which the interviewees in our study, both the heads of the services and the workers, highlighted repeatedly; the family is considered not only as an entity to be instructed and assisted, but also as an essential and necessary resource for the rehabilitation of the psychiatric patient.[4] Indeed, it is identified as one of the principal actors in the process and organization of care. The family's role is therefore redefined and it has gained importance to become the main focus for dialogue for mental health services. The new interactions between the mental health services and the family have led to different requests and, thus, different expectations, tools and resources. In the comparative literature on the welfare state, psychiatry assistance have represented a marginal theme. Social policy scholars have in fact concentrated mainly on the core sectors of the welfare state. Yet, the closure of the large mental hospitals in much of the western world has created the paradigmatic shift. However, the relationship with professionals has not always been benign. In this years it born a great deal of discourse about the experience between family members and services. In this field, moreover, research has tended to a large extent to focus on microsectoral aspects: family member needs and burden; participation in decision-making and relationships with psychiatric workers.

Current research tends to focus on barriers between families and mental health services, such as staff attitudes and inadequate communication with family members. For example, Slade *et al.* reported that family members were seen as pushy and demanding, prejudged if they tried to share information, and had to persevere in contacting services.[5]

Alternatively, Gray *et al.* found that family member were often discouraged from approaching services, and that they were seen as troublemakers and as part of the problem.[6] Gray interviewed sixty-five participants (directors, managers and senior staff from social, voluntary and healthcare organizations) who were encouraged to talk in detail about their understanding of family emotions. What emerged was a rich understanding of the broad spectrum of family members negative emotions (such as fear, anger and denial).

Participants noted a clear lack of emotional support for family carers, with accompanying feelings of marginalization, particularly during transitions and especially involving young family members as well as ethnic minorities. A year later, Gray proposed drawing up a covenant between mental health services and family carers, one based on mutual obligations.[7] He claimed that much of the relationship between families and services puts the interests of service users and providers ahead of family members and suggested that family members were hidden and invisible, trapped and isolated in narrow roles. Therefore, a covenant would help clarify what professionals expect of carers; and would ultimately improve engagement and relationships.

In Italy, the closing of lunatic asylums and the nationwide development of local services to treat people with psychiatric disorders and return them to the community have put these people back in their original social context and, especially, in their family. Currently, the assumption is that much of psychiatry is oriented to the involvement of family members in the rehabilitation therapy of the patient. But, when family members considered to be collaborative? Currently, in Italy lacks a literature

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that examines, in particular, the construction of the relationship between operators in psychiatric services, family and territory.

The main objective of my research is to observe the intertwining of issues involving people with mental suffering, their families and services. The starting point is the concept of the family as a resource for the entire mental health service but: i) the sense of failure and *denial of illness* which often creates an obstacle to a collaborative approach; ii) another obstacle to collaboration lies in the latent sense of guilt in family members; iii) obstacle to collaboration could derive from some staff behavior and not only from the family with its problems. From this final point of view, collaboration is something that mental health services and family should approach from a position of parity and symmetry, with both sides reacting to the other's behavior and attitudes. As Ferruta says, the complexity of a structure lies essentially in its organization.[8]

Hence, it becomes evident that those in charge should attribute positive worth to every sector of activity carried out within it, so as to make the unit work in function of the patients' needs and the workers' job satisfaction. It should not be overlooked here that the building up of relationships with the family, or with family associations, could, first of all, make it easier to listen to people who, though they may lack specific technical or scientific knowledge, are still people, to cite Creer with a wealth of experience which can be of use.[9] This experience should be exploited, since no system of treatment can work adequately and efficiently without complete collaboration from family members, without their first-hand knowledge and without a mutual sharing of the task.

Materials and Methods

The material for this study is extrapolated from interviews with health care workers. The interviews showed that the problems to be investigated were predominantly in the interpersonal sphere, that people's subjective impressions carry great weight, that society's interpretations of mental illness are significant and that everyone has their own personal cultural viewpoint. The study was therefore orientated towards qualitative systems of analysis. Structured interviews were conducted among 26 health professionals that included psychiatrists, psychologists, nurses, rehabilitation professionals, social workers and head nurses. Differences in age and gender were considered when the interviewees were chosen.

The study was carried out at the Public Mental Health Services in Rome, also because there were links there with another, wider-ranging research project (it is an interdisciplinary research project drawn up by Dr. Maone, head of the Via Sabrata community, RomeA, with the participation of Prof. Barazzetti of the University of Calabria, Prof. Cammarota of the University of Messina and Antonella Torre, an operative in the Mental Health Services).

Results

The starting point is the concept of the family as a resource for the entire mental health service; a concept expressed across the whole range of interviews. These parents who have to deal with their son or daughter's schizophrenia are usually no longer young and may have some physical problems of their own, since onset of schizophrenia usually occurs between the ages of 20 and 30. These mothers and fathers will all tend to have different ways of facing up to the difficulties and of expressing their pain. In some cases, in the absence of parents, brothers and sisters will come. Given that nowadays the majority of these services recognize the importance of family involvement by drawing up formal intervention plans, when family members considered to be collaborative? We put this question to the operatives in the various structures during the interviews.

But we are always looking for collaboration... Sometimes you find the family in agreement and willing to collaborate. Other times, they appear collaborative, but actually are ambivalent and in opposition. But the important thing is to build up a relationship with the family and proceed. (Galia, Psychiatrist, CSM RomeD)

Well...yeah...at first there is some reluctance […]. I must say that...mainly it's reluctance connected with the fact that, when parents send a son or daughter to us, they are unconsciously in competition with the community,...because, in a way, the separation, entering the community isn't something they view...it's seen as a problem, there's a sense of failure. (Leopold, Psychiatrist, Community RomeB)

Galia is psychiatrist in the a Mental Health Centres, while Leopold is a psychiatrist in a Community which frequently works with family members, also using multi-family groups. Galia thinks that the essential starting point for a collaborative approach with the family is for them to express agreement with therapy and treatment. Non-acceptance by the family of the specific nature of their relative's disorder becomes an obstacle. Galia makes it clear immediately that, even when this expression of agreement is not there at first and the family has an attitude of opposition or ambivalence, the possibility of building up a relationship with the family is still a priority for the mental health service. Galia thinks that a collaborative approach is connected to how and whether family members accept the patient's disorder. The need to obtain the family's agreement to therapy and treatment is seen as something in which the service must invest energy and resources.

Leopold too talks about reluctance on the part of some family members which often becomes an obstacle to collaboration with the service and which is usually a consequence of a sense of *failure* or impotence. Yet, taking a longer view, Leopold makes it clear that, even when there are difficulties at first, the results can be amazing if pathways to mutual understanding and collaboration are created with the family. Making the effort to work with the family brings gratification and excellent results, once the initial difficulties are overcome. An essential ingredient for a collaborative approach is acceptance on the part of the family of their relative's situation. *Denial*, as Galia and Leopold talked of too, has deep roots. These roots spread back to the process of stigmatization which society has applied to mental illness, deriving from the centuries-old view of madness as something frightening.

Only a few studies take into account this stigmatization process, which involves people close to psychiatric patients such as family members. They too become victims of the social exclusion strategies which lead to a sense of shame and isolation in addition to their suffering and despair. As discussed by Hatfield, unlike other unfortunate events which can occur in the private family sphere, such as death or a physical illness, in the case of psychiatric illness sometimes the structures of socially formalized assistance and sympathy seem to be lacking.

The sense of failure and *denial of illness* which often creates an obstacle to a collaborative approach, here are the stories of some events experienced by other staff:

A personal memory of mine was[…] a widowed mother with a schizophrenic son, the schizophrenia wasn't responding to medication[…] this boy caused a lot of problems, in his neighbourhood and in his family. […] When you set a sectioning process in motion, with signed documents, the police, two doctors and all the rest, well that's a big thing. When they got to the house, the mother would say: No, he's all right now *[…]. This is an example of how a parent can be passive and aggressive at the same time, first they ask for help and then they refuse the help. […]. Then…you get the parents who can't be collaborative because they are psychotic themselves. (Mustafà, Psycologist, Community RomeB)*

Mustafà here illustrates the ambivalent attitude, present not only in this specific case, which causes parents to swing perpetually between fear and love, between despair and a

search for protection. This attitude can be seen as a consequence of the fear of the son or daughter's reaction when the sectioning procedure is set in motion, but there is probably also fear of being abandoned by the institution which assists them. In the light of this, the road to information and awareness that the mental health services constructs with the family is an essential prerequisite for a relationship of trust. It is prevalently the chief nurses who express a concept of collaborative care which implies practical and concrete participation, to assist the mental health services.

If we ask them to.....well, say....to act in a certain way, like Don't come too often *or* Please phone before you come*, you know, not turning up unexpectedly without saying they're here.....they mustn't go into the rooms.....and they do as we ask [...]Everybody has stuff to do, sure...But the patients aren't just parked here, we do require basic co-operation.[...] It's true that we all have things that take up our time, but if you really want to, you can make time for something [...](Ellen, Head nurse, Community RomeB)*

We do believe that parents and family are of great value...Sometimes they can reach places we don't, for example...if a patient is reluctant to take medication, a parent or other family member who has been well instructed can be a great help to us. Also, if we give health education and explain what the early symptoms of a crisis can be, then sometimes we can avoid hospitalization...That means they also have an actual financial value, in terms of costs to society. (Crisanta, Head nurse, CSM RomeD)

In these cases yes, having contacts with the family that helps in giving medication; I have the prescriptions written out by the doctor and then I give them to the family.....sometimes a mother will telephone to say Look, he didn't take his medication today*. (Isabel, Nurse, CSM RomeA)*

Ellen, who works in a residential community, says that the kind of collaboration that the mental health services are often *obliged* to ask the family for, because they lack either the staff or the time, is everyday tasks such as health checks with the doctor. When the family refuses to do this, Ellen interprets it as an offloading of the patient by the family onto the mental health services. Ellen's worry is that a residential community could become, in the eyes of some people, a sort of alternative to the old lunatic asylums. For Ellen, *non-abandonment* and this kind of participation is a yardstick for measuring family collaboration. The community where Ellen works does in-depth work with the patients' families, both to have immediate support during treatment and to recreate relationships with an eye on the future.

Crisanta sees the collaborative assistance which is requested from the family as the services need for an *extra eye*, which checks and monitors the situation outside the structures of the service itself. The family thus takes on an active role in the therapeutic process and its management, as well as being an external support for the service. For this to be successful, however, it is necessary to work *with* the family, by giving them instruction and information about the warning signal symptoms which precede a crisis and about the importance of the patient following correct methods of medication.

Isabel, like Ellen and Crisanta, helps to clarify the difficult points where the services cannot be effective on their own. In her view, family participation and collaboration is essential as an extension of the services' efforts, as something which enables them to work better. What Isabel actually makes clear is that, in spite of limited contact with family members and the difficulties encountered with them, the services' real need and proper attention towards the patient are elements which can create a scenario where collaborative work with the family is a real possibility. It is clear so far that the majority of the workers interviewed in this study, even those who *technically* have less contact with the family, see collaboration as something which has to be constructed together. This attitude is also found among the psychologists:

I mean, family collaboration can become something more than just.....o.k. I'll try to check that my son or my wife takes the medication...and you get the family noticing behavior which is completely different from usual and telling us about it[...]. You have to build it up through meeting them[...]. But collaboration doesn't always happen straight away. If only it did![...]The main obstacles....well denial of the illness. Very, very often there's denial; some families say Oh no, you say he's ill, but he's not.... *(Magda, Psychologist, CSM RomeD)*

A collaborative parent is one who says: Doctor, I've noticed that my son is doing this or doing that, maybe it has significance for you*. Then maybe I'll call them back to say:* You were right, it was a good thing you pointed that out to me because it let me work on that aspect*. Intrusive is when they say:* Look here, you have to see that things are just not going right here*. [...] They criticize our work, the way we go about it; they say* You don't understand the kid, I'd better explain him to you. *[They do it]as a defense strategy[...] (Beverly, Psychologist, CSM RomeD)*

The family may be non-collaborative for two reasons: first when they are disturbed themselves; and second, when the medical staff don't create an alliance because, in their own minds, they believe that the parents are actually responsible for the disorder. (Mustafà, Psychologist, Community RomeB)

Magda and Beverly are both psychologists in the same Mental Health Centre, yet here are two people, in the same structure with the same professional role, who define collaboration differently. Magda is one of the few interviewees who emphasizes the importance of collaboration viewed first and foremost as a journey to be made with the family. Its basis is the ability and the need, not just of the service as a whole, but of each individual worker, to create a relationship with the family, through meetings and continuous dialogue. She believes that is the only way to obtain a type of collaboration which gives support to both the patient and the service. Magda also thinks that non-acceptance of the patient's disorder is an obstacle to construction of collaborative relations with the family. In her view, it is necessary to make every effort to surmount this obstacle as soon as it appears.

Beverly makes it clear that she only considers the family collaborative if there is an *a priori* respect for the workers' professional training and knowledge, with no intrusiveness; in other words, the family should have implicit faith in the professionals' opinion. Here a detailed outline of the actions and the practical interventions necessary for a definition of *collaborative* is not given, just an indication of the attitude required by the worker of the family to facilitate its involvement in the care program drawn up for the patient: the attitude consists in respect for the healthcare professional. While Beverly too sees family collaboration as a support for treatment, in her opinion an obstacle to collaboration lies in the latent sense of guilt in family members.

Thus, Magda and Beverly both consider a successful collaborative process with the family to be an effective tool for the worker in treatment of the patient, but have different opinions as to what constitutes an obstacle to its creation. On the one hand there is a belief in the possibility of creating collaborative pathways, also by overcoming human failings, but on the other the building of bridges seems to be compromised by the massive sense of guilt that families have. The constraints on collaboration created, in Beverly's opinion, by the sense of guilt, which Leopold also spoke of using the word *failure*, are viewed from an opposite point of view by Mustafà. He observes what could be a mistaken attitude on the part of the mental health workers; the apportioning of blame. Mustafà is the only interviewee who, on identifying an obstacle to collaboration, suggests that it could derive from some staff behavior and not only from the family with its problems. From this point of view, collaboration is something that mental health services and family should approach from a position of parity and symmetry, with both sides reacting to the other's behavior and attitudes.

Discussion and Conclusions

The study did not reveal a common way of interpreting collaboration between mental health services and patients' families. Indeed, the interviews contained various points of view which, in most cases, tended to neglect the way workers should be and concentrated on what the family should do. Even though the various healthcare professionals have different ideas about collaboration, practically all the mental health services in Rome included in the study intended to continue to attempt collaboration with the family. They were aware, however, that many obstacles can be encountered: i) the sense of failure and *denial of illness* which often creates an obstacle to a collaborative approach; ii) another obstacle to collaboration lies in the latent sense of guilt in family members; iii) obstacle to collaboration could derive from some staff behavior and not only from the family with its problems.

The study also shows that, in spite of all the structures included in the study having specific guidelines for ways of meeting with families, the actual relationships vary not only from one structure to another, but also between the staff members in the same structure. One of the main contradictions that emerges is the fact that in some structures, despite there being, in theory, a common code for collaborative action with family members, a grey area appears, within which individual workers have their own interpretations of what this actually involves. In the light of this, the tools and resources that the structure actually employs in practice are just as important as the theory in mediation of the relationship with the family. It was also observed that, very frequently, when the mental health service gives added value to all types of worker by actively involving them in work with family members, then each individual worker has a higher opinion of the worth of their job. This leads to an improved capacity for empathizing with the family, which the worker sees as needing support and assistance, as well as being able to give these things.

Seeing things from this perspective would mean that the mental health services must create places where workers and family can meet and establish a dialogue, so as to deepen the understanding of the daily difficulties that the family has to face. In conclusion services should create moments, such as multi-family groups or groups of information , managed by nurses and not only by doctors. These actions promote better collaboration. These occasions it might facilitate the meeting and knowledge between professionals and family members.

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