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The Hospital-Home: from the somatic experience to integration in the community, socio-cultural reintegration after 27 years of hospitalisation

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Summary

Institutional work with families whose children suffer from chronic illnesses represents a great challenge for both healthcare and support staff, including psychotherapists. I therefore put forward an action plan for family work for use in the primary immunodeficiency department of a chronic diseases hospital for patients suffering from serious genetic disorders. One of the particular features of this department is its work with the Roma community, in which consanguineous marriages often lead to genetic immunodeficiency.
I describe the clinical case of a young man, aged 28 years, who is still being treated in the pediatric department, and who, because of his ethnic and cultural heritage (as a member of a Roma family), along with his family has to live with double marginalisation. This 28 year old man, who is on the brink between life and death and has only limited contact with the outside world, is faced with the anguish of non-acceptance and of exclusion, because of the simultaneous presentation of his illness and ethnicity.

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Keywords: institutional work, chronic illness, family listening, cultural identity, double marginalisation.

Résumé. *L'Hôpital-Maison: de l'expérience somatique à l'intégration dans la communauté – la réintégration socioculturelle après 27 ans d'hospitalisation*

Le travail institutionnel auprès des familles dont les enfants souffrent de maladies chroniques représente un grand défi pour les personnels de santé et de soutien, y compris les psychothérapeutes. Je propose donc un dispositif de travail familial dans un hôpital spécialisé dans les maladies chroniques, dans le service d'immunodéficience primaire, pour des maladies génétiques graves. Une particularité de ce département est le travail avec les familles roms, où les mariages consanguins causent souvent une immunodéficience due à l'héritage génétique.
J'illustrerai le cas clinique d'un jeune homme de 28 ans, toujours traité en pédiatrie, qui, en raison de son appartenance ethnique et culturelle (membre d'une famille rom) vit avec sa famille une double marginalisation. Cet homme de 28 ans, à la frontière entre la vie et la mort et n'ayant qu'un contact limité avec le monde extérieur, est confronté à l'angoisse de la non-acceptation et de l'exclusion, en raison, à la fois, de la maladie et dethnicité.

Mots-clés: travail institutionnel, maladie chronique, écoute familiale, identité culturelle, double marginalisation.

Resumen. *Hospital-Hogar: de la experiencia somática a la integración en la comunidad - la reintegración socio-cultural después de 27 años de hospitalización*

El trabajo institucional con familias cuyos hijos padecen enfermedades crónicas es un gran desafío tanto para el personal sanitario como para el personal de apoyo, incluidos los psicoterapeutas. Así que propongo un dispositivo de trabajo familiar en un hospital de enfermedades crónicas, en el departamento de inmunodeficiencia primaria, con enfermedades genéticas graves. Un tema especial del departamento es el trabajo con las familias romaníes, donde los matrimonios de consanguinidad a menudo causan inmunodeficiencia debido a la herencia genética.
Ilustraré un caso clínico de un joven de 28 años, todavía tratado en la sección de pediatría, que debido a su afiliación étnica y cultural (parte de una familia romaní) vive con su familia una doble marginación. El joven, que se encuentra en el límite entre la vida y la muerte y que sólo tiene un contacto limitado con el mundo exterior, se enfrenta a la angustia de la no aceptación y la exclusión, tanto por motivos de enfermedad como de origen étnico.

Palabras clave: trabajo institucional, enfermedades crónicas, escucha familiar, identidad cultural, doble marginación.

Working with families whose children have chronic illnesses is a great challenge for both health care professionals and psychotherapists. Six years ago, I started a volunteer program in Bucharest at a pediatric hospital known for its chronic and critical cases. The program takes place weekly, for five hours per week, at the primary immunodeficiency ward. Due to the prolonged nature of the disease, I have been working with the same families all these years, with a few new families receiving this diagnosis and requiring chronic inpatient care in recent years. Very few of these families left the hospital indefinitely, unfortunately except for cases of death.

My job is to work with families who are experiencing dramatic chronic illness situations. These situations involve both a separation within the family and a separation from the community they are part of. During these years I have identified the importance of cultural identity and how strongly these families are affected by its loss and the loss of direct connection with the community. After many years of hospitalization, the illness and context around it become a collective unconscious way for the patient and his family to keep a sense of belonging adapted to this new way of living. This means, symbolically, that the disease becomes important for the patient and his family to be able to have a new sense of family, cultural identity, and of belonging, all related to the hospital environment and the other patients and their families.

The beginning of therapy

“Mihai” (pseudonym) was already a patient when I started volunteering at the Pediatric Immunology Department six years ago. He is a young Gipsy, 28 years of age, and is diagnosed with primary immunodeficiency. I have been seeing Mihai and his mother twice a month for 6 years, in a private room of the Pediatric Hospital where he was hospitalized almost permanently due to his illness and the various complications that appeared. Mihai’s weight is the main reason he is being treated by pediatricians at his age; until recently he weighed 21 kg. When he turned 18, there was an effort made to move him to an adult care unit, which was very traumatic for him and his mother, so his pediatricians insisted he continues treatment with them for an additional period of time.

Mihai is the only child of a Gipsy family from a poor region of Romania, the only male descendant of his extended family. His mother described him as the most spoiled in the family and everyone tries to help him and make him feel better. The father is a singer of traditional Gipsy music (he plays the accordion at weddings, baptisms, or on the streets of the big cities in Europe), while his mother has been a housewife since Mihai was born. It is fair to say that for Mihai and his mother the hospital has been home since he was born.

When I met Mihai he was 22 years old, had the appearance of a 6-year-old and the speaking skills of an 8-9 year old child. Initially he was very shy and did not talk at all. He always wore a red hat to hide behind, which I later found out he actually wore to hide white patches he had on his face because of the disease. His mother always described the whole situation as very tough, she did not make eye contact, and she would always gaze at some point above my head, no matter what she was doing, talking or just glaring. Our interactions started with me becoming familiar with their medical history. His mother had a very coherent way of explaining everything and used precise medical terms. Even though she only continued school through 8th grade, Mihai's mother was very familiar with the terminology.

In the first sessions, I found out that the mother was dressing Mihai, prepared his meals and drinks, and at the time he only used his own hands to eat. Mihai had never prepared a single drink or snack at that point. It often came to my mind that he will not make it alone when his parents will no longer be alive. He and his family most likely couldn't even imagine this version of reality, I think they believed that Mihai will be the first in the family to pass away.

The only inheritor to this family is seriously ill, the heir who can carry the family name on. Mihai did not go to school, even his doctors couldn't perceive the need for school in Mihai's case, meaning not even they could perceive the idea of a future for him. The beginning of therapy brings about the possibility of thinking both the present and the future for the first time (the present and the future not only from the perspective of the disease).

This stage was characterized by a void of thought, a white thinking, where there is no future, no body, no symbolizing skills, no mentalization (Marty, 1980), everything is symbiotic especially the mother and child connection, in a time and space that has no boundaries. Mum cannot concretely perceive her child's vitality and therefore does not give him tasks or anything to do, does not help him become responsible, the only way she can make sure the boy is alive is by infantilizing him, not allowing time to progress, as this would only bring the inevitable.

Middle stage

Mihai's situation severely worsened in October 2016 when he contracted an in-hospital viral infection and suffered a complication that spread to his lungs. He was then moved to another hospital and for two months I did not see him at all. I kept in touch with his doctors, who told me he's getting worse and his chances of recovery after this infection are minimal. One day the good news came that Mihai was doing better. Later, I was called by his mother and informed that they will return to the hospital where I am based and that they want to begin therapy again. I found Mihai to be very weak, I often thought maybe we were approaching our last meeting, he had difficulty speaking and he was very scared. The doctors came up with the suggestion of installing a subcutaneous port for more effective management of treatments. Mihai refused this procedure, motivating the refusal by fear of anesthesia and by the fact that this should take place in an adult hospital.

There were a few meetings in which this was the main subject of discussion, the fact that he was not ready to stay for a few days in an adult hospital and treated as an adult, and moreover to be deprived of his mother. After long talks, he accepted the subcutaneous port and was moved for a few days to a nearby adult hospital. The next meeting he was quiet and we resumed past discussions about the friends he spends time with at home and the fact that his mother is very excited that he is treated by youngsters his age as one of their own.

This success, with Mihai on his own at an adult hospital, brought along a new stage in therapy, the stage in which the boy started to develop. After this episode, due to the increased effectiveness of the subcutaneous treatment, Mihai's condition improved a lot, his eating started to improve, and therefore the treatments continued to prove even more efficient.

Two years ago, starting in the spring, the idea of Mihai’s transfer to an adult ward specialized in immunodeficiencies emerged in therapy. This possibility was vehemently denied by him, but especially by his mother’s reasons which she considered to be medical. Mihai’s separation of his mother was unthinkable, there was this symbiotic relationship between them, as if a separation of any kind equals death.

Mihai’s mother often said she felt like she's was being kicked out of her own house, she was symbolizing the children's hospital as home.

The family was trapped in a paranoid position, in which everyone who discusses the transfer to the adult section of the boy (26 years old) becomes hostile and potentially dangerous. Then a real war begins between the mother and the medical staff, in which the mother defends her right to remain in treatment at the pediatric hospital.

Cultural identity

In Gipsy communities, people live in small groups called *Satra* (a term that does not have a translation in other languages, similar to a tribe), a nomination specific to the nomadic Gipsy groups. The Children’s Hospital is, therefore, their “satra”. The Gipsy people are known to be very loyal to their family and their tribe, so most of the marriages are consanguineous, so as to not leave the community and to stay in the family. This is why the separation from the Satra that kept Mihai alive for 26 years (the hospital) is unbearable. Traditionally, Gipsy families are extremely symbiotic, with cultural identity being very important, which is quite visible in this case.

In Romania, Gipsy communities are found in poor villages at the periphery of big cities, and they no longer operate as nomads except through the characteristics of their crafts. Although marginalized, the Gipsy are highly valued for their skills and used by the Romanian population. Most men have jobs that have this nomadic character (musicians, builders, cobblers, metalsmiths, jewelry craftsmen, etc. that go to big cities to sell their goods or services). Women, on the other hand, live in their native villages, take care of their homes and children, many children in most cases, are recognized to keep their homes clean and appreciated as good housewives.

The Gipsy family structure has a very traditional character, couples rarely divorce, everything rotates around everyday life and the household. School education is traditionally of little importance, trades are passed down from father to son, even musical instruments are learned "by ear", although recently Gipsy families have begun to encourage their children to attend musical studies.

Mihai does not seem to be able to inherit any of his family talents, he cannot be a craftsman, he cannot be a musician, he cannot even go to school. He is even blamed for the fact that his family could not have other children, due to the poor condition of his health. The fact that his mother lived in complete symbiosis with him for so many years led to the fact that there was no more room in this family for more children.

Mihai has vitiligo blotches on his face (patches of skin that lack color). These spots appear to symbolically represent a mixture of his Gipsy identity (dark skin) and the obscure identity of his long-term hospitalizations (white, porcelain skin), as none of the doctors who treated Mihai are part of the Rom culture (Bucci, 1997).

Separation is experienced by the mother and by the young man as if something is ripped away, which is quite traumatic by itself, but moreover in this case there is the notion that he has two choices, either to live, to start growing both physically and mentally, within the capacity of symbolization, or to die (Andre-Fustier, 2011).

Mihai's relocation to the adult ward represents his hope of becoming an adult. Until the amazing improvement in his health, no one in his family thought Mihai could ever reach adult age. At birth, it was predicted that he would die, like in a gypsy curse, but a curse was given by the medical system. The only boy of the family is to be born with this serious health problem, spend all his life in the hospital, never get married, and have no children of his own. This situation is perceived by the parents as an extremely real gypsy curse. Mihai's mother has learned many medical terms in order to be able to decode this curse.

Mihai has grown 27 cm in the past two years and gained 20 kg in body mass. His appearance is that of a 15-16 year old child now. These are some amazing signs of progress from a medical point of view.

The certainty of the transfer brought a lot of anger to the therapy sessions. Anger toward the medical staff that does not act according to Mihai's best interest. When I mentioned this feeling, Mihai's mother said she feels kicked out of her house because this hospital (the pediatric hospital) has been their home for the past 25-26 years, there were always together, spent holidays and birthdays here, and this is even where they have learned that some colleagues lost the fight against the disease. Mihai has become more and more silent in therapy sessions, and his mother has become more vocal, as if taking his defense, and would argue that he is still a child who has to have the attention of a children's doctor, in order to remain a child. The mother felt anger, the rage that she was excluded from the hospital, just as she is excluded from the Gipsy Satra. It was as if she was living a double marginalization and a double exclusion, first of all, from the Gipsy Satra (the Gipsy community) because she has a sick child whom she has lived with for 28 years in hospitals, and second of all, from the hospital which once felt like a "home" because of what she perceives as the "*injustice*" of Mihai becoming an adult. This separation was experienced as the destruction of this symbiotic link as if Mihai was being thrown away. This link kept the child and mother alive for 28 years, there is a link of emotional dependence, the addiction is so great that separation means destruction. Mihai's father travels to keep himself alive. But it seems that the father is the only one who can cooperate with the fact that Mihai is so ill, raising the hypothesis that maybe his connection to the community is the difference.

During the discussions about moving to the adult department, the relationship between Mother and Mihai, on the one hand, and doctors on the other hand, began to be more and more difficult. There were many disputes at that time (as in any separation, as a symbolic adolescence).

The relocation to the adult ward means Mihai's first opportunity to became an adult, an option no one thought of until the beginning of the therapy. In the initial discussions with the medical team, all the prognoses indicated a life expectancy of 5 years. This was six years ago. Mihai has defied this limited hope of life, and now his doctors say he can lead a life close to normality, in which life expectancy is no longer a limiting factor. This is thanks to his progress, but also due to medical progress in the last several years.

The beginning of the therapy brought about the possibility of starting the mentalization process, brought the third person, the third person who has the ability to perceive the future, the possibility of becoming an adult.

Therapy also means a long process of mediation between the corporeal and the social, to think for the first time of Mihai's life and how he is outside his long-term hospitalizations and his illness. Through the therapy, a narcissistic reinvestment was attempted, both the mother and the boy regained confidence in doctors and medicines when Mihai recovered after the somatic fall in 2016. For the first time, they realized that they don't have to be physically together, next to each other, for all of the members of the family to continue to exist.

The end

Lately, Mihai’s life has changed a lot, he has made a group of friends that he has known since he was little, and who recently started to take him to city outings, parties, meals. These boys are Gipsy just like him, they are about his age, and they are traditional singers at weddings and baptisms. They protect him, care for him and always call him, tell him jokes, and make him laugh.

Mihai talks kindly to his friends, boys, who are passionate about cars and computer games. They talk about girls, some of them have wives and children of their own. It is as if these friends are Mihai’s new Satra, as was the hospital and medical staff so far, but the young group expressed the nomadic character, through mobility, and in general the cultural identity that Mihai needs so much.

Mihai continues with homeschooling classes. When he is at home he goes twice a week to a teacher’s home to take individual lessons in Mathematics and Romanian Language.

Now he can speak for the first time about other people in therapy, not only about his illness and suffering but about his friends, about his concerns about how he is viewed by other people, about still being very weak and having vitiligo (the patches on his face). He recently found a special cream on the internet that covers these spots (a kind of concealer), which symbolically covers the white patches and he is able to maintain his Gipsy appearance.

His medical condition has improved considerably, he is now undergoing treatment with subcutaneous immunoglobulins, which means that he is given the infusion alone, by himself, lasting about 3-4 hours a week. Although initially, he was very upset when he heard about this opportunity, to “move home” and refused, after a while, he renegotiated with the doctors and agreed to do his treatment alone. He recounts that when it is the day of the week when he is given the infusion, his parents “look for a job in the city” and leave home to avoid seeing the procedure. This mode of administration allows him to stay home, he comes to the hospital about once a month now, for prescription renewals and therapy.

Mihai now has the appearance of a teenager. For him, gaining autonomy meant entering adolescence.

Last year, in February, an idea in therapy appeared, to learn how to drive a car and to take the driver's license exam. It was for the first time that the idea of the future was present, a plan for the future.

He participated in driving school and after several attempts (he was always rejected in the legislative trial) he received approval to drive the car.

His very happy parents immediately bought him a personal car. He used all his time at home to drive his friends around in his car.

This year, in April, he had an extremely serious car accident, in which he had little time to lose his life, he was driving at an illegal speed and he lost control of the car.

The family then "separated" into two, his parents saying that they would not allow him to drive anymore, and them also feeling very guilty and saying that they really wanted him to be able to drive again, because the act of driving the car is his biggest, but also his only success. Mihai could take his defense very vehemently.

Mihai's ego is still fragile, he does not have the capacity to protect himself, as he still relies on the Gypsy community (his friends, parents, police officers, etc.). It is still necessary for him to be aware that the danger of death exists also without the manifest disease, and to be aware of the social dangers he faces (the car accident occurred when he was racing another friend through the village).

The guilt Mihai experienced after the accident was very great, almost overwhelming (for the first time in 6 years of psychotherapy I saw him crying). The guilt came from the danger he exposed himself to, from destroying the car, but it may also be a pang of survivor's guilt, compared to the immunodeficient colleagues (his other family), the guilt of healing, the guilt of living his life, like a normal young man.

Conclusions

Six years ago, at the beginning of the therapy, the family of Rom origin seemed to face a painful future, that of losing their only child, their son.

The medical advances and the great desire to live, are making this young man live beyond everyone's expectations. If from a medical point of view he has made great progress, the question remains how he can reintegrate and live socially and culturally, a notion that has not existed in the history of this family for 6 years.

The struggle with his somatic afflictions seems to be under control, but his individual struggle remains to have a life in the community, a community that seems willing to take him back, after 27 years of hospitalization.

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