Back to the future: family responding to HIV/AIDS in the era of combination therapy

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1. INTRODUCTION

The Human Immunodeficiency Virus (HIV) infection is spreading around the world and its occurrence is having a strong impact on our times. An interesting aspect of the epidemic is the variety of issues that are related to it: not only at a biological and medical level, but and foremost at a social and cultural level.

Many disciplines have been involved in the quest for understanding and modifying the history of the epidemic: biology, immunology, virology and medicine have been focusing on the interactions between the virus and the human body. Social sciences, including anthropology, have been concentrating their efforts in understanding and trying to modify human behaviours and the interactions between human beings and their environment, which play a role in the development of the epidemic. This widespread interest in HIV infection is not only due to the global proportion of the epidemic, but also to the all-encompassing characters of it: biomedical, economic and socio-cultural factors are at stake.

All these factors come together and shape the image of Acquired ImmunoDeficiency Syndrome (AIDS) and the life of people living with HIV infection. People living with HIV/AIDS (PWHA) and those sharing their life are central characters in the history of the epidemic. PWHA and their families have to bear the burden of stigmatisation, distress, illness and the economic and social costs of this condition. They have to adjust to a new, difficult situation and find mechanisms to cope with it. The strong medicalisation and the cultural construction of HIV infection had determined a degree of neglect of this aspect in the discourse on HIV management. Family care and management of PWHA is embedded in a web of meanings that is worthwhile to understand in depth.

My own involvement in the history of the epidemic in Italy started in 1988, first by participating in an epidemiological study, and then while I was working as a medical doctor in a centre for HIV/AIDS care and research. At that time, I was involved in clinical management and home care of people with HIV infection. The epidemic was at its peak with respect to the number of symptomatic cases, demand
for health services and social consequences. Later, either as promoter of awareness and universal precautions to health workers or as responsible for a prevention program in different target populations, I had the opportunity to come across many different perspectives on the infection and the disease. These different experiences stimulated my interest in focusing on HIV/AIDS for the final research of my medical anthropology training.

One of the liveliest memories of my work with PWHA is the human experience of uncertainty, fear, suffering, tension and love I observed in the families accompanying members infected with HIV. My interest in the subject is supported also by the growing importance of the care and assistance for people with HIV infection provided by family and other informal caregivers. Their participation in care is basic not only for the well being of the sufferer, but also for the health services, relived from part of the assistance, in terms of costs and constrains. Nevertheless, their arduous efforts are often neglected in the statistics about AIDS care.

**OBJECTIVES AND RESEARCH QUESTIONS**

**General objective**
To describe the factors at stake in the response of the family to HIV/AIDS, when one member is infected, with special attention to the perspective of the caregivers.
To describe the changes in the familial interactions after the introduction of the new antiretroviral therapies (or HAART, Highly Active Antiretroviral Therapy).

**Specific objectives**
1) To analyse the individual characteristics of caregivers and care recipients which have a role in shaping the care-giving interaction
2) To describe the economic, cultural and social factors which influence the familial interactions when a HIV positive member is present
3) To describe the changes in the perception of HIV infection and in the behaviour toward the infected member of the family, after the introduction of the new combination therapies
4) To analyse the role played by the Italian family structure and organisation in the
Research questions

- What does it mean for a family when a member is HIV positive?
- Which factors influence the care giving in families of people with HIV infection in the Italian context and in different family structures?
- How did the introduction of the new antiretroviral therapies change the perception of the infection and how does this influence the family management of the infected individual?
- How is the therapy managed at an individual and family level?
- How is the disclosure process experienced? With the family members? With significant others? With the community at large?
- What are the implications (positive and negative) of care giving for PWHA from the perspective of the caregiver?
- How does the presence of PWHA in the family influence the relationships with the external world?
- Which are the living arrangements and the practical organisation in a family in which an HIV positive person is living?
- What are the sources of expenditures and the possible subsidies available for PWHA and their families?

With these objectives and questions in mind, I went to the field. With this thesis, concluding one year of studies in Medical Anthropology, I will share my experience and present my findings. To start I will introduce the people who have been informing my work to lead the reader into the world I wanted to explore. I will present the research design and the applied methods to explain the procedures I used and the constrains I found during my work. After that, I will give a description of the context in which the stories take place and present the themes that have emerged in the talks with the informants. Finally, I will draw some conclusions that can be used for further research and for practical application.
1. THE FAMILIES

In this chapter, I will present the families which constitute the study population. After a short introduction on the Italian family and its role in health, I will present the salient points in the narrative of the HIV positive subjects. By describing their views on family interactions and on illness experience I want to give a general picture of the family context before discussing the response to HIV infection. I will describe each family also for what concerns structure, composition and organisation, with a brief explanation on the living arrangement and socio-economic conditions. Finally, I will introduce the members of the family, with special attention to those I managed to interview.

THE ITALIAN FAMILY

The Italian family, with unique and homogeneous characteristics, has never existed: there have been various typologies along time, space and social clusters. Many sociologists now agree that past theory about the change from the ‘traditional’ to the ‘modern’ family structure is wrong. In this theory, industrialisation constitutes the turning point for the shift from the complex structure of the ‘traditional’ family, extended or multiple, to the nuclear family. Data on the history of the family in northern-central Italy do show a change in family structure with industrialisation, which gave a strong impulse to the formation of neolocal conjugal families. However, the historical perspective showed that a unilinear change towards nuclearisation does not exist. In Italy, a series of oscillations with different grades of complexity, depending on economic variables have characterised the family structure. It is worth noting the change in family relations, independently from its structure: from the patriarchal, where the roles are strictly defined by sex and age, with strongly asymmetrical power relation to the intimate conjugal, more flexible in roles and power distribution (Barbagli 1984, 474). Even if Italy has been peculiar in respect to other European countries for the higher proportion of extended and multiple families, nowadays the majority of the families have a nuclear structure. Parents and children, in decreasing number, due to a very low fertility rate (1.2 in 1990-1995 [UNAIDS/WHO Fact Sheet 1999]), live together in neolocal arrangements. As reported in Pitkin’s (1985) ethnography, the Italian family
ideology centres on the verb *sistemare*, the primary goal in life of any married couple. “Implicit in that imperative is the recognition that the best and most worthwhile things in life are to be realised only through the formation of a family” (p. 209). This ideology supports the well known *familism* of Italian society, based on mutuality, where tolerance for dependency and family collaboration are normal experience of family life. Even after the changes of modernisation, the idea of support due to members of the kin group is very much alive, “in a manner that maximises the advantages of autonomy and interdependence” (p. 224).

From a sociological point of view, other factors related to the structure of Italian society should be considered. The consumerist economy determined the need for increasing the total income of the family. This stimulated the participation of women in the job market. In addiction, women still bear the responsibility for the household: domestic chores and care for the well being of family members are among the basic tasks of the wife-mother in the family. In the Italian family the role of the *mamma*, mother-wife is prominent, and we can expect her to take over the main role in the care-giving activities. When the role of caregiver is added to the already demanding other tasks, women can experience conflict between the different roles. This conflict can become the basis of feelings of stress and burden (Mui *et al* 1998), as we will see in the case of some informants.

Litman (1974) has elaborately described the role of the family as a basic unit in health and medical care. He reviewed the interrelation between health and family and advocated for an approach that “examines not only the interactions of family members, but the totality of familial transactions within the context of historical time”. In his review, the author revised the influence of the family not only on the use of medical services, but also on the development, interpretation and management of the illness episodes. The family has the first say in recognising the sick role and puts in movement the ‘lay referral network’, which depends on social-demographic characteristics, family size and moment in the life cycle.

**THE FAMILIES IN THE RESEARCH**

The principal demographic and social characteristics of the informants are
THOMAS

Thomas (pseudonym) is 33 years old. He lives in a residential area of a village near Milan. He resides in a nice apartment with his parents, the maternal grandmother and two dogs. He is the second of two siblings: his older brother lives nearby, he is married, with a small boy of 3 years. His brother, who had the same drug addiction experience, is HIV negative. He comes from a middle class, quite traditional family. His father worked for an airline and was often away. His mother stayed at home to care for the children, except for a short experience as a radio broadcast director, when the children were already grown up. He also has a close relationship with his grandmother and with his aunt, his mother’s sister. Everybody in the family knows he is HIV positive, but he goes for the medical follow-up by himself and communicates very little to the other members about his health situation. Nobody in the family is afraid of being infected; they maintain the close physical contact to which they were accustomed. Thomas loves his family and thinks he has been lucky. He never lacked love and care from them. Thomas’ mother adores him, as do the other members of the family. He has always been considered the beautiful, lively, intelligent and brilliant son: transgressive, but smart.

He has a difficult relationship with his father, with whom he has always been in a sort of competition. He reproaches his father for not having been communicative, for always pretending that everything is fine. Initially he said that it could be very difficult for me to talk to his father, but, in reality, he was the one who did not want me to talk with his father.

Thomas has known he is HIV positive since 1990. He was 23 when he confessed his drug addiction to his family and took the HIV test. He had been using heroine from the age of 14 to 23 years, but managed to keep it concealed, combining his drug addiction with a rather ‘normal’ life. He found in the desperation of his family, to whom he confessed his addiction, the strength to stop heroin use. After a period of voluntary segregation, in which he concentrated on fighting his addiction, he found a job and decided to face HIV infection. He contacted a Non Governmental
Organisation (NGO) and started to participate in self-help groups. There, he was one of the healthier present and has experienced the death of many friends:

“I started [self-help group] in 92. We were 18. Six months later we were already 12. The experience in the group was wonderful on one hand and terrible on the other. I kept on growing fond of people who were dying”.

Thomas has always been a nice looking boy, successful with girls. Love has always been central in his life and now, after a disappointing experience with an HIV negative girl, he is convinced he has no hope for the future.

He has never been sick. In 1994, due to a decrease in his immunity, he started antiretroviral therapy. Since he started the combination therapy, in 1997, his body shape has changed and he bears the signs of lipodistrophy\(^1\). Now he sees himself as very ugly:

“I have changed a lot. I feel disgusting. In 1997 I was still normal, a handsome boy, with my hair. My face was not excavated. Now I feel ruined by the therapies, more than by the disease and I have really the face of someone who is seropositive: I cannot say anymore that nothing has happen”.

He is afraid of being sick, but he is tired and sad. He feels hopeless:

“These last 10 years I felt as if I was pulling an articulated lorry. Already in 1990 I lost my love and my health. I would have liked to die in 1990, but I did it. I quit heroine to make my parents happy, and I have pulled this lorry for all these years. Now the idea that I will never have a girl, a work and my health…. “.

Thomas has a good group of friends, who know he is positive and have always kept close to him, inviting him to go around with them and to enjoy life. He loves them, but suffers in facing their ‘normality’.

“They go on, and I stay behind. To see them marrying, having children, or going out to dance until four o’clock in the morning, while I cannot go out even until 10… It is difficult to confront myself with them”.

Thomas has been working in the past, but he quit. Now he does nothing, but spends a lot of time reading books:

“What gives me pleasure now, a relative pleasure, is to isolate myself from the world with a book. To stay, let’s say, three, four hours in another world, in another story, in another reality”.

He says he wants to die; he does not want to face other deaths. He is even afraid of

\(^1\) Possible side effect of the antiretroviral therapy, consisting in redistribution of subcutaneous fats in the body. The effect is mostly evident in the limbs and in the face. (More later on)
the moment in which his old dog would die. Lately he has been communicating this uneasiness to his mother, who takes it as a “knife stroke”, but does not know what to do. Thomas refuses any kind of psychological support; he does not believe in God, but rather is interested in the Jewish tradition of his father.

PAMELA

Pamela (pseudonym) is a woman of 38 years. Nice and determined. She lives in a village 35 km out of Milan, in the countryside, where she can take care of her chickens, bees and garden. An only child in a working class family, she grew up in close contact with her cousins. She went to school up to the age of 19. An activist in the church, she joined the movement of the young Catholics.

She grew up in a neighbourhood in the peripheral area of Milan: a place that was, highly involved in the drug market and use in the period of her adolescence. When she was around 18 years old, she was deeply disappointed by the people she frequented in the church, whom she used to trust a lot, considering that “they were as disgusting as the others”. In this same period, she met a man, he was an intravenous drug user (IVDU). She fell in love with him and started to use heroine herself. She became pregnant at 19 and while still on heroine, she had her first daughter. She left the child with her mother, left her husband and started what she calls her ‘Calvary’, spending time in and out from different Therapeutic Communities (TC)\(^2\). At 24, having been in hospital for the umpteenth time to get treatment for addiction, she felt an unusual strength and asked her mother to give her the last chance: to keep her home and to help her to take her life back into her own hands. She managed to succeed: she got a job, and fell in love with another man. Meanwhile, during a stay in a TC in 1986, she found out she was HIV positive. At that time, she did not realise the possible consequences of it:

“\(\text{You know, but you do not know. You don’t see people dying and you just postpone the problem.}\)"

The man she loved accepted her, with her past and her HIV infection. They had a

\(^2\) Special institutions, public or private, which, following different principles and methods, were aimed at the reintegration of IVDU to a place in the society. Normally the IVDU, once out of physical addiction, goes to live in these common houses and stay there following a program of psychosocial support that should prepare him or her to face a new life out of drug addiction.
child together. She worked hard in her job as a graphic designer, enjoyed the reconciliation with her family, and tried to forget about her HIV infection. She always refused the available therapies and did her best to make people around her forget her history of drug addiction:

“It was very hard to reintegrate into a ‘normal’ life. I had to bow down my head and accept the mistrust of the people around me. I was telling myself - you have to swallow all these -. I made such a mess of my life before”.

Everything was going fine, until about 5 years ago, when she started to be sick: fever, coughing and a diagnosis of PCP. For two/three years she was in and out of hospitals, sick with PCP, CMV, cerebral toxoplasmosis and recurrent pneumonia, all very serious opportunistic infections.

“Ituh, those were three years of battles, fighting tooth and nail. Even my doctor thought I would not make it”.

However, two years ago she managed to start the HAART and she began to recover. She gained weight, energy and her future and decided to go back to study, to realise the dream of going to university to study literature. Now she is pregnant again, waiting for her third child. She is afraid; she is not sure of how all this will sort itself out, but she is hopeful; she believes in God, a Catholic who is convinced that this will help her.

Now she lives with her husband and two daughters. Her house is big, on two floors, with a very nice garden. She quit her job when she started to be sick and obtained her disability pension (she had worked for more than five years). Now she takes care of the house and the family. Her husband works as a skilled worker. With the help of their families, they have managed to build their actual house. Her mother is living in a nearby house and forms integral part of the family. She is often with her, helping with the house chores and with the care of the daughters. She had a conflict relationship with her mother in the past, but the closeness and affection between them is very strong, now even more since Pamela was sick and the mother lost her husband.

Pamela’s husband, 38 years old, has a strong character too. At the beginning, he did not want to talk to me, but after lunch together, we were chatting happily about life and the week there after I managed to meet him alone. He always refused to have
the HIV test, despite the fact that they had sex without condom. He has a conflicting relationship with Pamela’s older daughter, who is 17 years old. He realises that this is a problem in the family management, but he cannot help getting angry about her attitude, which he finds spoiled and lazy. The younger daughter is 9 and gets along very well with her parents. The girls do not know about their mother’s infection. They assisted her when she was sick, but are not aware of the diagnosis. Now everybody in the family is happy for the new pregnancy of Pamela, but they are also worried about the possible repercussions this can have on Pamela’s health.

Pamela has experienced the death of many friends, people from her past, as the first husband or fellows of the TC, who died of AIDS. She thinks that family support and love, a positive attitude towards life together with the new therapies are what have kept her alive.

“When I have to swallow the pills it is horrible. It always reminds me of the virus, but if it were not for them I would not be here now, for sure”.

RENAITO

Renato (pseudonym) is a man of 45. He studied to be a radiology technician and has worked for a long time as an area manager for a company in Milan. He has been married for ten years and lives with his wife in a very nice apartment, in the nearby area of the city. In the same building live two siblings of the wife, the only people informed about Renato’s health condition. Up to now Renato could not figure out how or from whom he got the HIV infection. He suspects of his previous work, when, as a radiology technician, he was often in contact with blood, or of some past relationships, which he could not trace back.

While on their honeymoon, in 1993, he started to feel sick. When he returned, the doctor requested, among others, the HIV test, without previous consultation with Renato. The test result was positive and the immunity was already deficient. He contacted the health services and immediately started the available antiretroviral therapies and the necessary prophylaxis. The wife’s result was negative. She was terrified by the idea of being infected and for a while she panicked, keeping all of her utensils and belongings separated from those of Renato. After some time
however, she came to terms with the new situation, but their sexual life was spoiled forever.

In 1995 he was diagnosed with Atypical Mycobacterium infection (MAC) and was very sick. In 1996, he started the HAART and his immunity improved, recovering from the MAC infection. Now he feels well but he bears the signs of lipodistrophy.

Renato has a good job, as does his wife; they do not have economic constrains. They gave up the idea to have a child when Renato found out he was positive. At that time the hopes for the future were scanty, now they feel too old to have a baby. HIV infection came as the end of all the expectations for the future:

“We married at an older age and we had a straight and flat road in front of us, this [HIV infection] came as a tegolata”.

Renato and his wife have not had experience of death or contacts with other HIV positive people. They kept the secrecy and very much reduced their social life, especially in the latest period, when Renato started to feel like a burden having to lie to justify his change in body shape and behaviour.

**PINO**

Pino (pseudonym) is man of 44 years. Single, he lives with his mother and uncle, his father’s brother. He finished high school and started University, studying modern literature, but completed only a few exams. He has been involved in drug addiction from the age of 23 to 33 years and has been in prison twice for robbery, for a total of two years and two months. He has been through various attempts for quitting drug use and has stayed in TC. Now he says he is off intravenous drug use, but his mother and the signs on his arms do not corroborate his story. At a younger age, before starting to use heroine, he was involved in political activism with the extreme left movements. He reproaches his parents for not having reacted strongly enough when they found out about his drug addiction. Now his life is very ‘domestic’ and he spends much time reading. Pino’s mother is 70 years old, a very energetic lady, who has been through a very difficult life: her husband left her when
the two children were both drug addicts. She had to manage with very little money to run the house and to provide for the nephew, the first son of her daughter, who was born while the mother was still on heroine. She has always been a very hard worker and now she lives on her pension, with contribution from Pino and his uncle, both retired. Pino worked as a barman and is now on pension for work disability, after having paid enough contributions for social security. Their economic situation is enough to cover the expenses and to save some money for the future. Between Pino and his mother there is a “pacific cohabitation”, in which they help each other in the house chores. Pino has few friends from the old times, many of whom have died because of overdoses or AIDS. He does not have a partner, but he does not miss this kind of relationship, as those with friends are fulfilling and he can have sex with occasional partners. He says he has always been very open about his health conditions, communicating his sero-status to his partners and therefore always using condom in sexual intercourse.

He has known about his HIV infection since 1987, but he never had any opportunistic infection. He is sick sometimes, with high fever, but it lasts only a few days and goes into remission spontaneously. He is on double therapy. His chronic liver infection makes it very difficult to find the right scheme for HAART administration, but he has been doing fine with two drugs, for two years.

**UGO**

Ugo (pseudonym) is a 51 years old man. He lives in Milan, where he works in a large supermarket. He is married and lives with his wife and three children. One is from Ugo’s previous partner, one is from his wife’s previous man: both of them are 20 years old. One girl of 11 is their common daughter. I met them in their apartment separately and talked extensively about their family life. Ugo has a friendly open face and his wife, 36 years old, is tall, plump and very energetic.

He is from a southern family. The fourth of seven siblings, his father died when he

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3 Italian expression for sudden and unexpected appearance of a bad situation that literally refers to the fall of a roof tile on the head. I will come back to this metaphor as the majority of my informants used it.
was 20. He completed elementary school and then started to work and had a regular life up to the age of 24, when he started to use drugs, heroine and amphetamines, intravenously. Out of curiosity to understand what the girl he loved was feeling and experiencing through drug use, he began a drug addiction that lasted, albeit discontinuously for 21 years. While he was living ‘running wild’, his partner became pregnant and he convinced her to have the baby. Soon after that, she left and Ugo remained with the son. He then went back to work and tried to stop heroine use. However, things did not work out as expected and, although he met and fell in love with his current wife, he did not manage to quit drug addiction. Nevertheless, he has managed to go on with his work and family life in spite of the drug abuse, which continued until six years ago. Then, he sought help from a doctor and managed to stop definitely through controlled administration of heroine surrogate. His wife has always been supportive of him and has accepted him with all his problems. They have decided to take the risk of having sex without protection. She is still HIV negative.

The family economy is based on his income and some contribution from the two young boys. Unfortunately, he accumulated many debts while on heroine and is slowly paying them back now.

He knew he was HIV infected in 1984, when his sister convinced him to take the test. He felt disappointed; he was giving up drug abuse and so he interpreted the test result as a punishment and used it as an excuse to start again. Occasionally he went to have a blood check to monitor his immunological status, but he never started any specific therapy. Two years ago he started to feel sick; he could not swallow and was losing weight. When he went to the doctor, he was immediately admitted to hospital to treat a bad oesophageal Candida (a fungal infection). At the same time he was diagnosed with tuberculosis and was treated. After recovery, he started the combination therapy, with great benefit.

When he was sick, he spoke with the two sons and told them about his health condition and about his past: they reacted positively, getting closer to him. The young girl still does not know. He is hopeful for the future; he would like to see his
children growing and a change in the general attitude toward PWHA.

“They have to understand that what happened to me can happen to everybody, to their children. I would like AIDS to be considered like any other illness: severe, but without discrimination. Because in reality that is how I take it: it does not influence my life more than a cold”.

Ugo has few friends as many others have died:

“Friends? Only one is left. He is also HIV positive. The others have all died. I have seen a lot of them disappearing”.

He feels rejected by his family of origin, as if they were ashamed of him. He feels discriminated by them. For this reason, he does not talk to them about his problems. He regrets all the opportunities he has lost because of drug addiction, for which he is still plying the consequences.

**LUCA**

Luca (pseudonym) is a man of 46. He is short and thin; his well-shaped muscles cannot completely hide the signs of lipodisprophy: thin limbs and expanded stomach. Luca is talkative and extroverted. He is living in a nice apartment in the suburbs of Milan with his mother, his father died 15 years ago.

Luca works as an interior designer in a shop in Milan and likes his job. The family lives on his income and on the pensions of his parents (the father had a reversionary pension). At home, the mother takes care of the routine management of the house, while Luca helps with harder work and sometimes cooks.

In adolescence, he realised his homosexual tendencies and, after a period of confusion, he accepted his homosexuality around the age of 18. He talked about it with his mother, but not with his father, afraid that he would not accept it. He has a very strong bond with his mother.

“My mother is protective of me and I am protective of her. It is a kind of symbiotic relation. To tell you the truth is a bit obsessive”.

After the initial shock, Luca’s mother accepted his homosexuality and now she receives Luca’s partner, whom he has loved for 14 years, as part of the family, as ‘a mother-in-law’. In the same way she knows and accepts his friends, a gay couple that has been always very close to them. They both were aware of the risk of HIV
transmission, but Luca indulged in occasional sex without using condom.

“At the beginning I did not know; then it was like a game, like playing Russian roulette. I had my friend, but at the same time, I had some occasional, unprotected intercourse. I don’t know why, on the spot I did not think about the risk, but afterwards I was remorseful - my God, what did I do?! -”.

In 1994 he took the HIV test, which was negative. He repeated it in 1997, as he was feeling sick, with fever and sore throat. This time the test was positive. His immunity was low and he immediately started antiretroviral therapy. The first combination gave him many side effects: nausea, vomiting and a change in his body shape.

“It ruined my stomach. I had many problems with the time schedule for the administration. I felt so badly, my image changed and saw myself as ugly. I had a rejection and decided with my doctor to change the combination. Now I am not immunodeficient anymore and the quality of life is good”.

Now, since May ’99 Luca is taking three drugs, different from before and he is doing fine. He started to train in a gym and is now regaining control on his body shape: this increased his well being and self esteem.

Luca and his mother overcame the initial fear; they talk about HIV and follow all the news about the progresses in medicine. Sometimes they forget about HIV infection. A neighbour, a friend of Luca’s mother, whose two sons are HIV positive, has supported them both. She comforted them in the hard moments of initial shock and in illness.

Luca does not conceal his homosexuality, but has kept secret his sero-status: only the neighbour and his boss at work know about it. Close friends and other relatives are not aware. Luca thinks to his future, when he will retire and enjoy his time with the people he loves. He is afraid of the day his mother would die. He is afraid of being alone in the future.

**CLARA**

Clara (pseudonym) is a woman of 33. She married Marco in 1994 and they live together in a very nice apartment in a residential area in Milan. She is tall, thin, with a very charming smile. After high school, she went to the Polytechnic for design and now she works as graphic together with a friend.
She is from a well-to-do family, but she never had an easy relationship with her family of origin: too busy, too formal, she did not find the care she needed. With a difficult adolescence, she could not wait for the moment to live by herself.

In 1993 she had to be operated on for an ovarian cyst. In the blood test done before the operation, the doctor also performed the HIV test, without previously informing Clara. The result was communicated to her mother, without her authorisation. She was desperate for a while, depressed and hopeless. She found out that a friend with whom she had a short relationship was also HIV positive.

She did not find a supportive environment in her family, except for her older brother, who has remained close to her. A few months after the test she reacted to her depressive mood and decided that she wanted to live her life positively. She met Marco, they fell in love and after a few months got married. Marco accepted her with no doubts and they have a satisfactory sexual life. They always had protected intercourse, but now they are thinking of having a child. Clara has been on antiretroviral therapy since the time she found out of her HIV infection. She started the HAART and, after a few bad experiences with compounds that gave her bad side effects, since one year she has been taking three drugs, 13 pills a day, with no major problems.

Clara and Marco love nature. Every weekend they go in their house in the countryside, where they ride their own horses and even participate in competitions. She is satisfied of her life and feels ready to have a baby; she trusts the therapy and thinks she wants to take the risk.

Clara informed very few people about her HIV status. Looking back now, she regrets having told some friends.

“I see them less now and every time I meet them I feel as if they couldn’t overcome the idea of me as HIV positive. I feel as if they are looking at me thinking I am always fighting against this thing, not at me as something else. They always ask how I am doing, which annoys me a bit”.

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Marco shares with her the responsibility of the house, but they have a person who helps them in household chores. Clara likes to cook and she has always been into macrobiotic and natural cuisine. She regularly visits a homeopathic doctor, who provides her with treatment for the general well being and the balance of her energies.

Marco works for the family company and Clara is a freelance graphic designer, their incomes together guarantee a good economic support.
1. RESEARCH DESIGN AND METHODS

JUSTIFICATION

I began to involve myself with the AIDS epidemic in 1988 and I stopped working as a clinical assistant in an HIV service five years ago. At that time, the new therapies were only being used in limited clinical trials for their registration in Italy. Thus, I could not directly witness the changes brought about by the introduction of the HAART. I was very curious then to know what was going on in the lives of people living with HIV and taking the new drugs. In addition, my previous experiences in home-care had left me with strong memories about family care giving. These personal motivations were the heart of the choice of the topic of this research.

To make the work even more interesting was the fact that the information resulting from it could be useful also for other people. While talking to people involved in the daily history of HIV infection, I realised that the perception of the infection was changing and new issues were emerging as HIV infection was a less severe condition. A shift in perspective was taking place, not only for the HIV positive subjects, but also for the people taking care of them.

After a year of anthropological studies in which I realised how far reaching the cultural and social aspects of medicine were, I was expecting that the changes, occurring in AIDS epidemic, would also entail a change in meanings, expectations, perspectives, human relations and possibly collective construction of the disease. To look at the emerging issues from the perspective of PWHA, with particular attention to their caregivers, it would have given the opportunity to realise what they were experiencing and eventually to recognise unmet needs and perspectives for the future.

I planned to disseminate the report of my research to the people who have been involved directly or indirectly in it, hoping that it can constitute the basis for further discussion. The staff of the Infective Disease Department, which I contacted for the
recruitment of the informants, seemed interested in the topic. They suggested me that a big change was going on and welcomed the idea of an anthropological research. I also contacted some people working in a NGO for assistance and solidarity with PWHA. They anticipated that my work might be disseminated through their journal, where it can become the starting point for further considerations on some aspects of family life.

Finally, from my point of view, to go back to a subject that I have known from a medical perspective and to look at it through the anthropological ‘gaze’, was a unique occasion to exercise newly learned skills and to practise a new point of view. I propose all these as justification for this research and for the possible inconveniences that I gave to those I involved.

\textit{METHODOLOGY}

\textbf{Study type}

Due to my previous experiences in the field of AIDS I had some basic knowledge about the context in which PWHA were living, at least for what concerned medical problems, social needs and fear of stigmatisation. The unit of analysis in my research is the family and the changes brought about by the combination therapy in family interactions. This was a totally new subject for me, so I decided on a qualitative, descriptive study, aimed at giving a comprehensive picture of attitudes and practices involved in living with HIV in the family. The cognitive character of the research questions and the complexity of the themes under study justify the qualitative approach.

At the onset, I had some assumptions about the subject of my research:

1) from the literature and my experience, I was convinced that PWHA were living in families, mostly with parents. An Italian study (Marazzi 1994) found that 55\% of PWHA living at home were staying with their parents, less with siblings, friends or spouses. In reality, as soon as I started to look for families of HIV positive subjects living with their parents, I realised that this was not the
most common arrangement anymore. The increase in mean age of PWHA and the better health status implied that many PWHA were now living alone or in couples, sometimes with their own children. I decided then to look for informants that define themselves as living in family, independently from the family structure. I only excluded homosexual couples, because of the limited frequency of homosexuals in the AIDS scenario in Italy and because, in general, this group has been already the subject of many studies.

2) The second assumption was about the effects of the distribution of the new therapies. In Italy, antiviral regimens with a two-drug combination were available from the end of 1995. The more recent Protease Inhibitors have been licensed in Italy since the beginning of 1996, and the combination therapy, best known as HAART, was available for all the patients during the second quarter of 1997. Since then, changes in survival among people with AIDS have been reported through experimental and observational studies (Porta 1999). The history of the epidemic has been changing and many changes are still underway. The HIV positive individuals are now facing a new stage in the epidemic, in which the disease becomes chronic, with a much lower probability of progression to the final stages. The family has to go through a readjustment: it is no more a question of accompanying a dying person to his/her last period of life. Now the question is to support in dealing with the effects of the therapy, with the possible return to work (Brooks et al. 1999), with the disclosure of a lasting condition, still stigmatised in the community.

**Study setting and sample**

The fieldwork took place in Milan, the regional capital of Lombardia, the second largest city in Italy, where I have been living for thirty years and where high prevalence of HIV infection is reported. The data collection started in June 2000 and was concluded in the first week of July 2000.

The research focused on the family response to HIV infection; therefore, the study population consisted of families in which a member is infected with HIV. My working definition of the family, as previously described, became more flexible
after the beginning of the fieldwork: the family was whatever was defined as such by the HIV positive subject, whom I will call the index case. In fact, I talked with people with very different kinds of familiar organisation.

Following the assumption that the introduction of the HAART is changing the response to the epidemic, only people infected with the HIV virus, living with their family, who have been on antiretroviral therapy for at least six months were included.

Another necessary characteristic was that the family was aware of the HIV status of the index case. My interest was in attitudes and practices of the family, especially of those who have to deal with ‘joys and sorrows’ of PWHA daily. Therefore, they had to be aware of HIV infection. This condition complicated the recruitment, because many of the PWHA living with parents did not disclose their status to the family.

The informants were contacted through an Infectious Diseases Department, Centro San Luigi, a special unit for care and research on HIV infection and correlated syndromes. This Department is part of a very big, private hospital, which is operating within the National Health Service (NHS). PWHA attending this clinic are assigned to a medical doctor, who becomes the reference for the medical management. The access to this centre is free for whoever wants it and presents the request of the personal General Practitioner from the National Health Service. People attending the centre come from different sectors of the society.

I asked the doctors working there to pick out among their patients, subjects with the characteristics I was looking for and to ask them if they were willing to participate in the study. Once they gave their permission, I contacted them directly by telephone to arrange the appointment for the interview. Nobody refused to participate, but I had some difficulties in setting the appointments due to the full schedule of some of the informants.

Thus, I made a convenient sampling from a closed cohort, those attending this Department, whom I considered quite representative of the HIV positive population.
I contacted and interviewed seven families, with different structure and organisation, as described in the previous chapter.

**Data collection techniques**

I collected the data mainly through in-depth interviews, using a semi-structured open-ended list of questions (see Appendix 2). The interviews were taped and transcribed in the original language: Italian.

I had to arrange the interviews in different locations: I met some of the PWHA in the Clinic, some at their home and some in mine: I left the choice of the place up to them. I interviewed the other members of the families in their own home; this gave me the opportunity to observe the living conditions, the arrangement of the space in the house and other characteristics of the family management.

I tried to interview the positive subjects first and then the other members of the family. I collected the life histories of PWHA. Through the reconstruction of significant moments in their lives, I could access the themes that are significant to them. I tried to focus on “what the personal narrative can reveal about the culturally specific processes having an impact on their life” (Pamphilon 1999).

Each other member of the family was interviewed separately, except in one case, which I greatly regret, as I realised that the conversation was not totally free. This strategy gave me the possibility to apply some triangulation of sources, as the same stories where reported by different members of the family.

In the initial work plan, I scheduled a Focus Group Discussion with the caregivers. After the first contacts with the families I gave up the plan, due to time constrains of the informants and to the sensitiveness of the topics.

In addition, I contacted and interviewed four key informants, chosen in order to have a more general overview of family perspectives, services available and medical care for PWHA and the changing history of the AIDS epidemic. The main key informant was Dr. Massimo Cernuschi, who has been working in infectious
disease since 1983. He has been through the entire history of the AIDS epidemic. His work is mainly clinical, with activities in the in- and outpatients departments. Massimo is also an activist, working in an NGO founded by HIV positive people, named ASA (Associazione Solidarietà AIDS=Association for Solidarity against AIDS) and based in Milan. This NGO offers counselling, home-care and self-help groups for HIV positive people and their families. They organise prevention programs for the general population and many other activities to socialise the problems of infected people and to create solidarity toward them. Massimo was my colleague for 4 years, when I was working in the same hospital and in the home care group in ASA. His key role is due to his long experience in AIDS. As a doctor and as a friend of many HIV positive people, he has a realistic and ‘experience-near’ attitude towards the epidemic, joining professional knowledge and human understanding.

Another key informant was Marianne, whom I met in ASA. She does some voluntary work there and is the mother of an HIV positive homosexual man. She represents the subjects I was interested in and she ‘went public’; therefore, she is involved in raising awareness on HIV infection. Her position in the NGO and in the society made her a perfect informant for discussing the issues on family perspectives.

The third informant was Dr. Silvia Nozza, who works in Centro San Luigi as well. She is a young doctor. For two years she has followed the Ambulatorio Prime Visite, the service where people who want to be followed in the HIV clinic attend their first visit. Therefore, Dr. Nozza is the first contact for people coming from other centres or those who have recently discovered to be HIV positive. I was interested in the perception of the infection in those who acquired the virus recently, in the era of HAART. Moreover, I wanted to know what kind of message and information these people were receiving from the health services.

Finally, I visited a home for HIV positive mothers and their children, created and managed by an NGO with subside from the public administration. Three years ago Archè (the name of the NGO) opened a house where HIV positive mothers with
children could find a place to stay and someone who helps them in responding to HIV infection and other social problems. I talked to the person responsible for this place. There I could find some information about people whose ‘family project’ could not work out and about the problems which women and their children had to face.

Data Analysis

The preliminary phase of analysis began during the data collection activities. Life histories were represented as “trajectories, useful in making sense of the work performed by patients…. in relation to illness and its consequences” (Castro 1998).

My findings reflect mostly what people told me. I did some observation while visiting the informants at home, but the stories of PWHA, their mothers and partners are the core of the data. Narratives are used very often in anthropological research and passionate debates have been going on about the use of narratives. All the transcribed interviews with the HIV positive subject were analysed and the emerging themes were presented to the other members of the family to increase the quality of the data.

The interviews were analysed and common themes underlined. During the interviews I heard different versions of the same story, but as Lawless (1996) underpins “narratives are not treated as necessarily true accounts, but nor are they considered to be false in any sense”. The narrative representation of one’s life and of the HIV infection experience should be interpreted as a reconstruction giving a meaning to the lived experience, ‘a rehearsed plot’. In an enlightening article, Kathy Charmaz (1990) proposes to look at chronic illness through a “symbolic interactionist perspective tempered by Marxism and phenomenology”. This perspective assumes that what people do depends from the meanings they give to the situation they are in, but these meanings result from social interactions and are constructed following subjective realities (phenomenology) and social structures.

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4 See the publications on Social Science and Medicine 1994, Vol.38, No.6 and Qualitative Inquiry 1999, Vol.5, No3.
(Marxism). A constructionist approach “assumes an emergent reality fundamentally shaped by social interaction… and offers flexible means of studying both fluid interactive processes and more stable social structures” (Charmaz 1990). I tried to analyse the data following this perspective.

**Limitations**

I present the limitations of the study to explain the possible bias in the discussion of the findings. Firstly, it was one objective of this study to describe the changes induced by the introduction of the combination therapy, but it is important to note that the cross-sectional design of the research is a limitation to this aim. In cross-sectional studies, the past is reconstructed through the recall of the participants, therefore is liable to plot making, in which “meaning is made to match the ending” (Pamphilon 1999). A longitudinal study would have suit better for the description of changes.

Secondly, even if I could not identify any factor limiting the access to the clinic where I recruited my informant, the selection of people attending the same health service may give rise to a selection bias. A larger study, selecting people attending different HIV centres, would have resulted in a more representative population.

During the final work of data analysis, I realised another limitation linked to the study design and to the sample characteristics. The absence of a comparative group hindered the possibility to compare and verify some considerations. While analysing the data, constructing categories and making comparisons I realised that the sample was not complete. The lack of diversified life experiences, like fathers of PWHA, families of PWHA who are not on combination therapy, children of PWHA and PWHA concealing their status to the family, prevent to corroborate my findings.

**Ethical considerations**

Before interviewing, I explained the purpose of my study and asked for informed consent to all the participants. Permission to talk with the other members of the family was previously agreed upon with PWHA. To guarantee maximal
confidentiality I concealed real identities and used pseudonyms.

Fieldwork experience

Going to the field as a medical anthropologist was an exciting experience. Due to my ‘sticky’ medical background and the lack in experience in anthropological research, the fieldwork and the data analysis turned out to be also a difficult challenge.

The first challenge was that of abandoning the quest for ‘homogeneity’ and generalisations. As a medical doctor, I was trained to bring back the specific to the general, the exception to the rule. Even if in medical studies the singularity of every individual is part of the background information, the biomedical paradigm demands for its functioning generalisation and ‘statistically significant’ information. Therefore, when I had to deal with the narratives of the informant, I started to panic: such different stories, such diversified experiences, how would I manage such a variety? The background, gained through work experiences and studies in medical anthropology, helped at least in avoiding the transformation of panic into despair.

In addition, I was working in my own country: what about my third rebirth? (Srinivas in Nanda 1998, 30) Would I be able to recognise cultural patterns in which I have been ‘drenched’ since my childhood? I am quite sure I have lost many clues that someone, outsider in Italian culture, would have noted. Nevertheless, I could recognise some typical cultural patterns, especially concerning family life and experiences of youth protest and drug addiction. These were for me of great interest as are part of my own life.

Anyway, I went to the field, decided to find an answer to my questions. Contacting the informants was not difficult, I still had good connections with the HIV services and everybody showed interest in my work and was very helpful. Difficulties started with the interviewing as people were eager to talk, but it was hard to keep them on the track of my guidelines. Partly thinking that for an anthropologist every piece of information can be useful in reconstructing the ‘native’ world and partly because I got involved in the conversations, I collected also information that were
not pertinent to my research topics. This cost me some telephone calls to ask basic demographic information that I forgot in the excitement of discussions about meanings and perceptions. Anyway, I had the advantage of repeated contacts with the study unit, the family, through the different members, which allowed me to retrieve information during the following contacts.

People were surprisingly open, we talked about sex, death, family conflicts and crime, all topics normally considered taboo. This experience confirmed my opinion about tabooed and sensitive topics: once the favourable conditions are created, where people perceive the environment as non-judgmental and confidential, especially with an outsider, it is easy to talk about sensitive issues. Exactly because the chances for discussion are normally minimal, but the need to face them great. At least, this is my experience.

Different is the issue about the truthfulness of what people say: I made a point of considering what people told me as true. Anyway, what they were saying was the message they wanted to pass over to me in that moment; I remembered the discussions about “performative ethnography” (Pool 1994) and the production of meanings.

Next came the challenge of data analysis, when all the issues about my background and lack of experience came back and renewed their confounding power. I decide to proceed scholarly. During the preparation of the fieldwork, I had drafted a list of variables concerning my topic and I filled them with the data from the field. In addition, I used some concepts from the available literature on my topic and from previous reading to deepen the analysis.
2. BACKGROUND INFORMATION

In this chapter I will provide the some basic information about HIV infection and the issues related to it. My aim is to frame the context in which the stories take place to allow a better understanding of the data presented later. In fact, some of the topics presented here will be discussed again, starting from the point of view of my informants.

I will present statistical data on HIV situation in the world and in Italy. I will discuss the Italian Law for AIDS emergency interventions, the inattention of which has caused great discomfort for people affected by HIV infection and those caring for them. I will present some information about the services available for positive people and the laws dealing with this subject. I will discuss some of the issues related to the new therapies that are changing the history of AIDS epidemic in the Western world and are at the centre of much of the current debates on inequalities of access to drugs. Finally, I will have a short discussion on the phenomenon of intravenous drug use, which, in Italy, is related with the diffusion of HIV infection and has very strongly influenced the lives of some of my informants.

THE STATISTICS

The AIDS epidemic has reached in a short span of time proportions that were unforecastable when the first cases were notified, 20 years ago. Statistics about HIV infection are always catastrophic and indeed the situation is alarming.

Following the estimations of UNAIDS, (United Nations Program for HIV/AIDS) at the end of 1999, 33.6 million people were living with HIV and 16.3 million had already died because of AIDS. In 1999 only, 2.6 million had died and 5.6 million were infected.

The distribution of cases follows the lines of vulnerability due to poverty, lack of information and gender inequities. The most affected areas are in sub-Saharan Africa, where 70% of the world’s cases are found. The World Health Organisation (WHO) and UNAIDS have estimated that in 1999, there were a total of 12.2 million
infected women and 570,000 new cases of infection in children under the age of 15 in the African continent.

In September 1999, the 11th International Conference on AIDS in Africa was held and the alarming data on the infection were discussed: AIDS is now the principal cause of death in southern and eastern Africa. For the year 2010 an increase of 75% in infant mortality is expected and more than 6 million orphans because of AIDS are already present in sub-Saharan Africa (Gruppo Abele 2000).

The data available not only illustrate the situation of HIV infection around the world, but also sketch the future of some African countries, where HIV infection affects people in productive and reproductive years.

**HIV infection and AIDS in Italy**

In Italy the prevalence of HIV infection is among the highest in Europe; 20% of all European AIDS cases (AIDS Care 2000(12):120) are found here. The infection which started among the intravenous drug user (IVDU) population in the early eighties, has also spread to the general population, mostly through sexual contact.

Data on the prevalence of HIV infection are scarce, but the National Surveillance System (COA, Centro Operativo AIDS) estimated that at the end of 1999, 104,000 people were living with HIV/AIDS in Italy. The prevalence is higher in men, but it is growing faster among women. The number of notified cases of AIDS by the end of 1999 was 44,924, of which 14,743 are still alive, as reported by the National Surveillance System (COA in Gruppo Abele 2000, 29). The most prevalent modes of transmission are needle sharing among IVDU and unsafe sexual intercourse among homosexual and heterosexual couples. The distribution of AIDS cases by mode of transmission, as reported in the notification forms, reflects the prevalence of risky behaviours and their changes over time.

The data from UNAIDS/WHO Epidemiological Fact Sheet of 1998 report: 64% of total AIDS cases acquired the infection through needle sharing in drug injection, 13% through homosexual or bisexual intercourse and 12% through heterosexual
intercourse. Only 2% of AIDS cases are due to transmission via blood products and 1% is due to mother to child transmission. For 8% of AIDS cases the mode of transmission is reported as unknown. In the data based on AIDS notification of the National Surveillance System\footnote{It is important to remember that statistics are based on notification of AIDS cases, as HIV infection is not subject to notification in Italy. Thus they reflect the trends of transmission occurring some years before and are influenced by the changes in life expectancy of the infected population.}, in 1999, for the first time, the transmission through sexual contact (homosexual and heterosexual) exceeded that of transmission through needle sharing, representing respectively 48.5% and 43.4%. This change is due to the evident increase in transmission through heterosexual intercourse, while the rate due to homosexual sex has been more or less stable over the years. The shift towards an older age of the notified AIDS cases is another important change. Male AIDS cases in 1989 were 45.5% and 47.4% respectively in the age-group 20-29 and 30-50. In 1999 those rates became 7.6% and 75.9%. The group over 50 also increased. The trend is very similar for females. The mean age of AIDS patients is now 38 years for men and 35 for women. The statistics of the first six months of 1999 show that 10% of the notified cases, in that period, is represented by immigrants living in Italy. (COA in Gruppo Abele 2000, 56). Studies of IVDU in different major urban areas in Italy showed HIV prevalence varying from 36.8% to 60% of the tested groups (UNAIDS/WHO Epidemiological Fact Sheet 1998). In general, big cities show the highest prevalence of HIV infection, due to the high prevalence of population at risk and to better surveillance systems.

Milan is the capital of Lombardia, the most affected region in Italy. The city, where a high prevalence of HIV infection is noted, was an interesting setting for this research, as all the actors in the AIDS epidemic in Italy are present.

The first case of AIDS in Italy was notified in 1982. In the following years, the potential development of the epidemic was underestimated by the scientific community, the policy makers and the population at large. Nevertheless the spread of the infection, in Italy and abroad, attracted the interest of mass media and other institutions. They contributed to the representation of the epidemic, thus influencing the perception of infected people and attaching fear and stigma to the infection, as I
As the epidemic spread, some Italians experienced the infection in their own environment, giving a more “familiar” face to the infection. This lead to a smoothing of the accusing and stigmatising attitude. Still, fear, misinformation and prejudice often accompanied people living with HIV/AIDS in the community, though at a lesser degree.

**THE SERVICES AND THE LAW**

In Italy, once diagnosed with HIV infection, a person can go through a procedure that will allow him or her to obtain free access to medical services. This is a kind of *rite de passage*, which introduces the person to the new status of seropositivity, with all its personal and social consequences. This procedure implies the necessary disclosure to the General Practitioner (GP), who has to make the request for the visit to the HIV services and for the exemption from health costs. It also implies contact with the services and other infected people. Therefore, it represents an obligatory ritual for the HIV positive person who enters into a different community, marked with the *stigma and stigmata* of the infection. The contact with this new community has different effects: for someone can be the occasion to meet people with whom to share concerns and suffering, for others can mean the difficult coming to terms with the images of the disease.

“It was so hard for me to be there and see all these sick people. I did not know what it means to have AIDS, I did not want this to happen to us” (Renato’s wife).

“I like to go there, it seems like …not really to help other people, but there I met other mothers, we talked. Yes, there I find… I cannot express it properly but I’m willing to go” (Luca’s mother)

Infectious disease departments all over the country have been overwhelmed by the flow of people in need of medical assistance because of HIV infection. Due to the delay in the planned expansion of hospital beds and to the growing number of people diagnosed with symptomatic infection, many PWHA did not have access to inpatient medical services and had to manage the situation with the help of their family and friends. NGOs committed to the prevention and care for HIV infected people reacted, covering the immediate needs, both medical and socio-economic, of these people and their families.
Some initiatives were taken in the public sector as well. The National Health Service implemented some emergency intervention. However, it was only in 1990 that the Government promulgated a Law (135/90) on “emergency interventions for prevention and fight against AIDS”, setting the due date for completion by the end of 1992. The program set the provision and the relevant financing of 6,900 hospital beds to be added to the 1000 already available. The administrative machine started to work and lot of confusion followed. To make a long story short, I refer to the report for the evaluation of the implementation of the Law, presented in 1996 by a special Parliamentary Commission of investigation: only around 690 beds of the ‘urgent’ 6900 have been added to the existing ones (Agnoletto 2000, 294).

Nowadays, the need for assistance for the infected population has changed a lot and the program, established in 1990 and never realised, is already outdated.

The same law also established community care services which should provide an additional 2,100 beds, 75% of which at home and 25% in hospices. The implementation was delegated to the regional governments, which were provided with the financial back up. Basically, the public services should try to guarantee nursing home-care, including intravenous administration of medicine and management of medical devices (urinary and venous catheters). The visit of a doctor at home, on a regular basis, would reduce the need for transportation to health services, the load of outpatient clinics and the permanence in hospital. In some regions the program was started, with great benefits for the patients and their families. The team of health workers was usually accompanied by a social worker, taking care of the administrative protocols and socio-psychological well being of the sick person. Again, it is very difficult to know where and how the program is working, the last data available date back to 1995 (Agnoletto 2000, 296). In Milan, the home care services were organised by the district health services and the coverage was patchy. In some zones it worked quite well; the medical team were providing the basic personal and nursing care, giving some relief to the families. In other areas the services never started, in spite of the available financing.

Since 1990, all HIV symptomatic people under a threshold income can ask for
financial support. The invalidity pension, supplied by the central government, is a very low monthly contribution (around 200 USD X 13 months/year), to which an additional amount is added in case of inability to perform daily activities (around 420 USD more per month). In addition, people who are recognised as invalid have priority in the allocation of public housing and free ride on public transport. This contribution can take up to three years in bureaucratic procedure and for this reason the local administration supplies financing in advance. In order to access this subsidy, a doctor should certify the health condition of the person, but the administrative offices guarantee no privacy on HIV status. In case of certified inability to work, those who have been employed and have paid their social security contributions for at least five years, can access a working inability pension, proportional to the paid quote. This subsidy is supplied for three years, and after this period the health conditions are re-evaluated and the right can be extended for other three years. In case of nine consequent years of inability to work, this temporary contribution is turned into a definitive retirement scheme (ASA-Augustus Foundation 1997).

Nowadays, with the changing health situation of PWHA on new therapies, this subject is under debate. Up to now the law is still enforced, but possible changes in the rules of the financial assistance are being discussed. A revision of the law implies new concerns about assisted people being re-integrated in the labour market. In the United Kingdom, a recent study on this subject was done and gave evidence to a range of concerns in the group of HIV infected people. They reported anxiety for a possible loss or change in the medical benefits, the need of finding a job flexible enough to allow for medical follow-up, the need to be trained for re-entering the job market after long absence and the worries about possible discrimination in case of disclosure of the HIV status (Brooks and Klosinski 1999).

The law on assistance and privacy is the final issue that I would like to address. The Law 135/90 art.5 states that health workers must ensure total secrecy about the test result. The test should be done on a voluntary basis and the result should be communicated only to the involved subject and cannot be discriminative for school, sport or work attendance. In 1994, a sentence of the Constitutional Court declared
art.5 partially invalid. It stated that HIV test can be imposed to those people whose working tasks can put other people at risk, but did not clarify which tasks are considered dangerous in relation to HIV infection. Again, the issue is matter of debate and fight for the activists, but some of the stories that will follow are clear examples of how the right to privacy and voluntary testing has been neglected.

THE NEW THERAPIES

In 1986, a double-blind clinical trial on the efficacy of azidothymidine or AZT, the compound that at that time was shown effective against the virus (Yarchoan R. et al. 1986), was interrupted after 24 weeks for ethical reasons. The group receiving the real drug was doing better than the one receiving placebo. From then on, AZT became the standard treatment for people with HIV infection, whose immune system was starting to show signs of weakening and for people in advanced stage of disease. Not all the patients could tolerate AZT therapy and it was soon clear that the virus was able to mutate into new variants resistant to AZT.

Many other drugs have been studied and tested, but no real alternative was available until the mid-nineties, when new compounds reached the clinical practice. More drugs became available and the importance of multiple drugs regimens was definitely proved.

Nowadays, in most European countries HIV infected people have access to what is called the “combination therapy” or HAART (Highly Active Antiretroviral Therapy). This is a cocktail of drugs, with different mechanisms of action, that work synergically in reducing the viral replication. The viral load can consequently be decreased to undetectable levels and the immune system is allowed to a progressive, even if partial, reconstruction (Gazzard 1996). This regimen is advised for symptomatic and asymptomatic subjects and acute or recent infections (see guidelines released June 19, 1997 by the U.S. Department of Health and Human Services).

Health services are free of charge for HIV infected people. The Italian Ministry of Health provides antiviral treatment for all individuals who need it. Therapy with a
combination of two antiretroviral agents started in 1995 and HIV-1 protease inhibitors (major compounds in the combination therapy) were available for widespread use during the second quarter of 1997. It followed a significant decline in the risk of death from AIDS (Porta 1999). After the introduction of the HAART, the clinical conditions of many HIV infected people have improved as to allow them to return to a more or less “normal life”.

Due to the efficacy of the HAART, the AIDS epidemic has been going through a great change. Especially for what concerns the medical and health services, there was a kind of ‘revolution’, which demanded a rearrangement of the services and new expertise from the doctors. HIV infected people do not get sick as much as before. The data from the National Surveillance System reveal that 60% of people diagnosed with AIDS in 1999 were not aware of their sero-status. A study realised in a referral Hospital in Rome reported that 21.6% of people were tested at a very advanced stage of the infection (Gruppo Abele 2000, 46). Those few data confirm what many of my key informants, doctors working in an Infectious Diseases Department in Milan, told me:

“They who really get sick with AIDS are the ‘unlucky ones’, who cannot take the therapies because of intolerance or resistance and those who do not know they have HIV”. (Massimo, doctor).

Still, the management of HIV infection remains problematic. The new therapies request high adherence to the administration schemes in order to maintain their effectiveness and heavily weight on the daily life of PWHA for their side effects and modalities of assumption. Presenting the results of an Italian study on compliance, the representatives of four associations of positive people affirmed that 20% of the subjects taking the new therapies quit the treatment, mainly because of lack of information (Gruppo Abele 2000). It is interesting to note that a study on treatment interruption, made by the medical establishment found a discontinuation rate of 36.2% and the main reason for it was toxicity, based on laboratory data, responsible for 21.1% (D’Arminio-Monforte et al. 2000). In this research, the reason for discontinuation was stated by the clinicians. My key informants, the doctors I talked with, reported of people having asked to stop the therapy because of
side effects, especially those that cause a total change in the body shape, such as lipodistrophia, as I will report later. Doctors have to learn to manage different clinical conditions that are not typical manifestations of HIV infection, like solid cancers, liver failure or metabolic changes rarely seen before. These changes have to be managed while the patient is taking a potent cocktail of different substances with possible interactions, about which we still know very little.

The medical discourse on HIV infection has changed and now proposes more ‘evidence-based’ conclusions to guide the decision-making process. Viral load and resistance tests, with quantifiable values, became the basis for therapeutic decisions receiving more attention than quality of life and individual well being. Nevertheless, doctors, ‘real’ people in front of ‘real’ patients, express many doubts and concerns in dealing with the current situation.

“The management of the therapy is not easy at all…I think the big mistake is that doctors have no idea what it means to take those drugs. You cannot imagine. You should have a holiday with someone taking the drugs to understand. Yes, doctors cannot imagine the suffering these drugs can give…The number of people refusing the drug is increasing, but it is a conscious choice. You have to think a lot before starting the therapy” (Massimo, doctor, activist in NGO).

No doubt, we are entering a new era of the HIV epidemic. The people who will benefit from the new therapy represent only a small percentage of all HIV infected population. However, the effects of this new possibility will dramatically influence the history of the disease in the rich countries and will have strong repercussions on the rest of the world, which still cannot access these compounds.

**INTRAVENTOUS DRUG USE**

We should not forget that in Italy the HIV epidemic involved the group of intravenous drug users, especially in the earlier period. The common use of needles and other instruments for the preparation of injection with an infected subject allows the transmission of HIV virus. In the following table, the attributed percentage to IVDU of the total AIDS cases is reported.

<table>
<thead>
<tr>
<th>Year</th>
<th>82-92</th>
<th>93</th>
<th>94</th>
<th>95</th>
<th>96</th>
<th>97</th>
<th>98</th>
<th>99</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>%IVDU</td>
<td>67.4</td>
<td>64.1</td>
<td>62.5</td>
<td>60.7</td>
<td>59.2</td>
<td>53.7</td>
<td>46.9</td>
<td>43.4</td>
<td>61.8</td>
</tr>
</tbody>
</table>

December 1999 - Centro Operativo AIDS of National Institute of Health (from Agnoletto 2000)
The slow decrease in time is possibly due partly to prevention programs and partly to the saturation by HIV infection in this specific population. Since 1987 a multicentre longitudinal study has been carried out to follow a cohort of HIV negative IVDU attending drug addiction treatment centres in Northern Italy (NISDA study). From this study resulted a decrease in seroconversion rate from 6.1% in 1987 to 3.6% in 1991 in a population of 1,063 followed IVDU. Younger age and a shorter duration of addiction, together with the provenience from areas of less economic development are characteristics associated with higher frequency of risk behaviour and HIV prevalence (Ciaffi et al. 1992). The reduction in conversion rates is associated to the reduction in needles sharing after the exposure to information campaigns (Molinari et al. 1991). This study also showed that sexual transmission “played a role in increasing the risk of acquiring HIV infection among IVDU that was distinct from and addictive to that of syringe sharing” (Nicolosi et al. 1992).

I think it is important to analyse intravenous drug abuse in Italy through a political-economic perspective to understand the origin and the context of a phenomenon that resulted so important in HIV epidemic. The history of drug use in Italy goes back many years, but it started to have a social and public health impact in the mid-70’s, a period of high social tension and open conflict between opposite groups in the society.

During the second part of the 70’s the terrorist actions of Brigate Rosse and the massacres secretly organised by state institutions in connection with the ultra-right movement created an environment of tension and terror (Soccorso Rosso 1970 and Mazzocchi 1999). The growing empowerment of the Italian Communist Party (PCI), tied to the working class movement, and the broad participation of youth, especially students, to the leftist movements was threatening the European balance in the cold war. The United States strongly supported the ruling party in Italy, the Christian Democratic (DC). This party had been ruling Italy since the end of the war, thanks also to its connection with the mafia and the church. In this context the extending protest of students and youth, constituted a threat to the established social order. The cultural background of the younger generation was a mixture of the
hippie movement coming from USA, which invited to explore the world of psychoactive drugs and a political commitment towards the working class.

Those were the circumstances under which the spread of intravenous drug addiction took place, resulting very useful for the conservative forces by reducing part of the protesting potential to the stunned silence brought on by heroine. The mafia controlled the market, and nothing was done to avoid its expansion.

The intravenous consumption of drugs, mostly heroine, followed by many other psychoactive substances (amphetamines, hypnotics and analgesic drugs), grew rapidly in the following years and involved an increasing number of young people. As reported from some of the PWHA, whom I interviewed, drug addiction was spreading very quickly and became part of their daily experience.

“At that time [77-78], it [heroin] was everywhere. In Rozzano [a suburb area of Milan] it was a disaster. You turned your head and could see people giving themselves a fix” (Pamela)

“My friends in high school were all involved in politics. We were of Lotta Continua [extra parliamentary leftist party]. Around half of them were involved also in drug addiction. Now they are all dead, either of an over-dose or of AIDS” (Pino).

The phenomenon was transversal in the society, involving young people from different social backgrounds, but it struck much more those already marginalised and in disadvantaged social positions. The number of drug addicts increased rapidly and became a major social and public health problem. At the beginning, the spread was highest in the suburbs of big cities and in the twenty to thirty age-group. It reached its peak in the decade of the 90’s. Deaths for overdose were reported constantly in the newspaper and the official statistics counted cumulative 15,790 deaths from 1973 to 1999. It is difficult to monitor the situation of drug abuse; indirect indicators are the statistics provided by the social and health services and from judicial and police proceedings, which of course cover only a limited percentage of the entire phenomenon.

In the World Day against Drug promoted by the United Nation (UN) some data about drug addiction in Italy were presented: officially in 1999, there were 137,567 drug addicts. This number represented only those who attend the specific services,
of whom 86.6% use heroine. The recent change towards new synthetic drugs, that seems to involve a number between 200 and 400 thousands people, is depicting a new scenario that still needs to be understood (Gruppo Abele 2000).

Since the beginning HIV entered in the IVDU population with disruptive force and became part of the addiction experience. Even if the specific services now indicate a decrease in the percentage of people found positive with the HIV test, only 16% in 1998 and the AIDS cases due to non sterile use of needles are tapering down. There is still a great need of programs that will adopt the policy of harm reduction and controlled consumption that showed their efficacy in other countries.
3. FOREGROUND INFORMATION

Before presenting the data and listening to the stories of the people whom I interviewed, it is important to gain a picture of the cultural context of the Italian society, and of the city of Milan, beyond the facts in statistics, laws and services.

In the houses, the health services, the medical community and in the public arena, everybody has a different picture, a different view of what is going on and, at the same time, is immersed in those of the others. It is important then to understand the context of the Italian situation in the year 18th of the AIDS era, considering the factors that contribute to the construction of the ‘reality’ for the people I decided to involve in my research.

After a short introduction on the social representation of epidemics, I will report on the construction of AIDS as a collective image and in the medical discourse. Both of these constructions influence very much the perception of the infection by the people who informed my research.

THE SOCIAL REPRESENTATION OF AIDS

HIV infection was declared a pandemic in 1987. Through this declaration the WHO recognised the world-wide spread of the infection and called for a general involvement in the fight against AIDS. No country is free from infection, but epidemiological and social realities in each place can be very different, shaping local perspectives and meanings.

Thus, an “epidemiology of representations” (Sommerfeld 1994) can be traced with the analysis of the societies that produce them. The construction of AIDS epidemic in each context is shaped by political and cultural circumstances.

Historians have been studying the past epidemics. They recognised a constant plot in the response to the perceived threat of an epidemic, which is, by definition, unexpected, of sudden appearance and often brings apocalyptic visions of contagion.
and death. Rosenberg (1992) describes the “dramaturgic form” of an epidemic and distinguishes a constant sequence which can be enacted in different ways depending on the local situation.

The first stage is that of gradual recognition and acknowledgement of the “intruding disease”. Epidemics are emergencies: to define the occurrence of a disease as epidemic implies a chain of events that are characteristic of the response to an emergency. Those events can go against the interests of some groups of the society and threaten the sense of safety of the community, sparking off social tensions and the search for someone to be blamed.

When the first cases of *Pneumocystis Carinii* Pneumonia (PCP) appeared in a group of young men in USA, nobody could easily foresee what was going to happen. Rapidly the number of cases grew and the parallel with the image of plague was proposed, rising the anxiety for what could come.

In Italy, the then-called “gay-disease” appeared in the news, for the first time in 1981 and initially did not cause a big stir; no alarm or specific reactions were developed. In 1982, the first case of AIDS was notified and in 1983 the Ministry of Health (MOH) circulated the description of the AIDS clinical case and called for the notification of all suspected cases. At this point the presence of AIDS in Italy was acknowledged.

Rosenberg (1992) defines the second stage in the history of an epidemic as that of “managing randomness” which is when the social construction takes place. The epidemic is there and “a collective agreement on an explanatory framework” is needed. This moment is crucial in shaping the response to the threatening disease. A common explanation has to be found for responding to the quest for control of the community and to the need of a framework, that minimises its vulnerability. The explanation should define the sources to be blamed and the way to control them.

The evidence of the spread of HIV infection among the American gay community was the epidemiological basis for the construction of AIDS image as a sexually
transmitted disease (STD). This potent and historically significant image, comparable to that of the five hundred years old syphilis (Gilman 1988), marked the initial definition of AIDS and is at the roots of much of the stigma and discrimination attached to it. The AIDS epidemic was constructed following the moral and social concerns of the dominant groups. As Gilman (1988) reports in his book Disease and representation: images of illness from madness to AIDS, “the social reality of the ‘real’ and ‘imagined’ disease is constructed on the basis of specific ideological needs and structured along the categories of representation accepted within this ideology”. There are different perspectives to analyse the social construction of AIDS. We should not forget that there is more than one image following different ideological needs and group interest, but one, from the dominant group in the society, normally imposes itself on the others.

From a psychological perspective, like that presented by Gilman (1988), diseases are a source of fear, anxiety about the limits of our own control on life, about the chaos brought about by the random strikes of misfortune. To overcome this sense of vulnerability, we build up distances between us and the diseased, “individuals whom we construct as being more at risk”. They are the ones who will fall victim of the disease, because of their special characteristics. This gives us the chance to maintain our “healthy” self apart from the Other, the one who is “on the brink of collapse”. This psychological mechanism lies as the basis of the construction of the AIDS patient as “both the victim and the source of his own pollution”. The source of pollution is located outside, in a person different from the dominant group. This Other changes in different contexts: the Haitians and the Africans in USA, the Africans and North-Americans in Europe and the Westerners in Asia. Within the same society are deviant subjects, - people moving at the margin of the dominant model: homosexuals, intravenous drug users (IVDU) and prostitutes are the sources and the victims of HIV infection. They are not ‘normal’; they deviate from the accepted models of the society. In Italy, this process followed very much the American model: HIV infection was a problem of the Others, those who were homosexual or IVDU, those of whom ‘morality was doubtful’.

In Italy, like in other countries, the disease was associated with “perverted sexual
behaviours”, lack of morality and drug addiction. The strong influence of the Catholic church on Italian culture contributed to the stigmatisation of the infected people. Conservative groups defined the disease as a “punishment of God” for the “immoral behaviour” of homosexuals and drug addicts. The Catholic influence on the government constrained attempts to provide neutral and clear information on safe sex and condom use. Programs for needle sharing were delayed due to moral stances. Episodes of intolerance and violence against HIV positive people were reported in different regions, as I will discuss next.

The third stage in the ‘dramaturgy’ of an epidemic is what Rosenberg (1992) calls the “negotiation of public response”. This means the action, policies and programs developed to control the threatening reality. The kind of response that is generated depends from the perception of the disease and the interests of the institutions and the different groups in the community.

The image of AIDS as a STD, linked to certain categories of people, namely the deviants, was very strong in Italy. When the first national campaign for prevention of HIV was launched in 1988, six years after the first AIDS diagnosis (sic), the message was addressed to the general public. It tried to promote the idea of risky behaviours, instead of that of risk groups and promoting condom use as an effective means of prevention. The reaction of the Vatican was immediate, proposing abstinence a means of prevention and contesting the promotion of condom. The Minister of Health soon released a letter addressed to 20 million Italians, in which he invited to practice a ‘normal sexual life’ to prevent HIV infection and alerting that condom should not be considered a safe means of prevention. (Agnoletto 2000).

This deviant vs. normal model has been maintained over time, despite the evidences against it. The persistence of this model can be explained with “the powerful secondary effect to the stigma” (Gilman 1988, 268). Believing that deviants, marginalised groups, are those who will be affected, guarantees to the rest of the community protection against the fear of their own vulnerability. The possible sources of infection should be avoided and isolated. The attitude of blaming the
victims has been going on up to now, often fostered by the media. The media attention to HIV infection is often related with news stories describing - often with names and photos - women, sometimes working as commercial sex workers (CSW), who are willingly infecting men through multiple sexual contacts. It is interesting to note that what comes to media attention as dangerous is most often the sexual life of women, who can be accused of homicide for sexual intercourse with the aim of contagion.

Paradigmatic to this attitude is the story which occupied the newspaper in February 1998. In many newspapers there was the photo with all the bio-data of a woman accused of being a prostitute, practising orgies and couple exchanges without using condom, knowing fully well of her HIV infection. This publication was requested by the General Attorney of Ravenna to alert the regular and occasional clients of the woman and two special telephone numbers were arranged to provide further information. This woman was accused of having voluntarily infected 5,000 people. No attention was paid to a law made in 1990, stating the right for privacy about test results. The comment of the Attorney was that “the right to privacy of the accused woman cannot prevail on the right to life of men who had had contact with her”. The story occupied the media for a while; journalist pestered the woman in her hospital room, where she was lying sick because of HIV. This woman was condemned in May 1999 to a one-year prison sentence for attempted aggravated personal lesions (Agnoletto 2000).

This story is just one among many of the same kind that has appeared in the media. What I find paradigmatic is the construction of the story and subsequently the image presented of HIV infection. First of all, the violation by the General Attorney of the right to privacy, in the name of an improbable ‘right to life’ of the clients, is indicative of the lack of attention given to laws governing basic rights in Italy. Second, the blame put on the woman is paradigmatic of the gender attitude and the blaming of the victim, occurring in the Italian context of AIDS. The woman, not her clients, is held responsible for not having used condom. Last, but not least, the handling of the subject by the media is paradigmatic of their role in the ‘misinformation’ about the real issues about HIV infection.
The fourth and last stage of an epidemic in Rosenberg’s presentation is that of “subsidence and retrospection”, in which the time come for the people concerned to “look back and ask…what lessons have been learned”. For the AIDS epidemic, it is difficult to define this phase. Despite the optimism raised by the statistics in Italy, which appear to show a decrease in the number of AIDS cases and of new HIV infection, the epidemic is far from subsidence and there are still many lessons to be learned.

Non-governmental organisations and some people from the Catholic church working directly with PWHA are promoting counter-information (Gallo 1998), which is not welcome by the Vatican, but is contributing in setting off the debate inside the church. The mobilisation of HIV positive people themselves is growing slowly, after long time of silence, caused by a fear of stigmatisation. The book by Agnoletto La società dell’AIDS, published recently, is an attempt to make the point about the AIDS epidemic in Italy. It reports about many scandals, injustices and discriminations against PWHA and proposes some considerations about the interests of different groups which have been delaying the response to the HIV epidemic.

The medical establishment has not been very active in the fight for civil rights of PWHA and for proper information. On the contrary, many doctors found that the attention dedicated to AIDS was excessive compared with that for other medical problems. I still remember some comments made by colleagues from other departments, asking why we were bothering so much for people who were dying and who deserved it. Pamela, one of my informants, told me of an episode she had experienced. She went to another department to have a blood sample taken. She was early, but in a hurry to go to fetch her daughter at school, she therefore asked the doctors in charge to have it done a little bit earlier. One doctor started to comment on her:

“He accused me of being manipulative. He had such a spite in his voice. I was so sad and angry. He treated me as I were not even a human being. ‘I can say what I want about this person, anyway she is HIV positive and possibly has been a drug addict, or maybe still is’. But even if I were, he has no right to treat me like this and I told him, without making a scene. I cried a lot about this afterwards ”.
THE MEDICAL DISCOURSE

In recent articles, published in medical journals, on HIV therapy, the efficacy of the multi-drug regimens or HAART (Highly Active Antiretroviral Therapy) is not questioned, but protocols are elaborated to answer some unsolved management questions (Garcia 1999). The current guidelines “emphasise early aggressive treatment using multi-drug combination regimens” as reported by Volberding (1999), one of the most recognised authorities in the clinical management of HIV infection. The studies done until now assessed the efficacy of the therapy, but the information available is enormous and often contradictory.

What are the main points about the therapy that can be noted from the available articles? I made a review of the recent medical literature on the new antiretroviral therapy and I will propose some considerations about the actual medical discourse on HIV infection.

The paradigms used to explain HIV infection and related diseases have been changing over time, reflecting the cultural dominant trends. Virology and immunology have been competing in lending metaphors to represent the disease and in guiding research, but “neither ultimately wins full explanatory power, and both must account for the logic of the other” (Patton 1990).

In the biomedical research, mostly based on quantitative, statistical analysis, the patient as a person is very often neglected, only to become the case of a disease or the acceptor of a new technology. In the first trials, HIV patients were defined by their age, sex, epidemiological risk factor, social background, immunological status and clinical manifestations (symptoms or opportunistic infections), not as unique individuals, but at least, as people, to whom one could attach some kind of identity and related socio-cultural context - even if stereotyped and superficial. These people could be related to suffering, to the enormous distress that HIV infection can cause.

This representation has been changing and in the most recent literature, other, more
biological, characteristics are used to define the ‘subjects’ in the studies. Virological markers became the main targets of medical attention: the individual is managed as the *carrier of a certain type of HIV*. Documentation about the virus is increasing, while characterisations of the sufferers are decreasing. You can read about the virus type, quantity, susceptibility and resistance, replication, suppression, rebound, long term reservoirs (sometimes called sanctuaries) and activity, while the subjects in the study are described only through their previous pharmacological history, risk of progression, development of AIDS, opportunistic infection and immunological status. In many publications, the patient regains his/her identity because of a lack of compliance to the pharmacological regimen, thus becoming a source of danger for the future and the community, a potential cause for the development of resistant viral strains.

There is a progressive detachment from patients’ real lives, and the construction of a new object, a biological container, that has lost even its human bodily characteristics. Still, many studies are based on ‘real life’ situations. Large cohorts of patients have been followed up and only clinical outcomes (the appearance from AIDS related symptoms or death for AIDS) considered, but the main concern is always to measure the efficacy of the drug combinations, expressed as risk rates for AIDS progression or death. I did not find any study, in the medical literature, concerning the possible change in the quality of life or the determinants of the well being of infected people, even if the influence of these factors on immune function is widely recognised.

As I mentioned before, the management and the relationship with ‘real’ people is far more complex. Apart from the diversified needs that go far beyond the antiretroviral therapy, the decision-making on drug intake is a constant process of negotiation between medical knowledge, patient’s beliefs, desire, possibilities and tolerability. The people with HIV/AIDS that have been stripped of their individuality and even of their bodies in the clinical trials, regain their uniqueness in the daily management of their ‘clinical’ life. However, this process of negotiation has not been yet considered in depth.
The changes in the medical discourse about HIV infection reflect the technological achievements and are supported by economical interests. The medical discourse in turn influences the development of the research agenda and the effects of the above mentioned changes are already visible in the agenda of the AIDS Clinical Trials Group (ACTG). The focus of current and future research is in the development of drugs to reconstruct the immune system and in defining the best rescue therapy for people with multi-resistant strains or for whom the available regimens failed. The research for the management of opportunistic infections is shrinking; there is no account of all the people who do not have access to the HAART and will still experience opportunistic infections as before. The management of such conditions was far from being satisfactory, but the research on the complications of HIV infection takes into consideration only patients on HAART. Great interest is reserved for ‘naïve’ subjects - those who never received any therapy, who are supposed to possess the ‘original’ strain of the virus, not yet ‘spoiled’ by contact with drugs (ACTG web site).
4. LIVING WITH HIV

The literature regarding family care giving to PWHA in western countries is rich: the majority of these accessible studies focuses on homosexual couples or on the family context in relation to the health services or to the terminal stages of AIDS. These studies describe activities (Wrubel 1997), and behaviours (Hayes 1994) of caregivers, the psychological distress (Irving 1995) and physical costs (Leblanc 1997) of care-giving activities and the coping mechanisms (Folkman 1997) used by people caring for HIV positive subjects.

These studies were mostly done before the introduction of the new anti-retroviral therapies; therefore, they analyse care giving in a period in which AIDS was still burdened with high mortality. In that situation, the care-giving role imposed a much higher demand on the family members. Nowadays, the effectiveness of HAART has changed the perspectives of the future and the general conditions of PWHA; consequently also the roles of family members have been changing and the family has had to adjust to the new situation.

Even if now it is widely accepted that the therapeutic possibilities had changed the life perspective of PWHA in western countries and therefore the meaning of living with HIV/AIDS, the literature is very poor on this topic. Few articles appeared analysing the issues at stake in the ‘new life’ of PWHA and those around them. None of these studies takes the family as the unit of analysis to explain the adjustment process to the new perspectives.

As Marianne, the mother of a PWHA, one of my key informants said:

“If you come to know that your son is HIV positive today it is very different. My experience goes back 15 years when that was very different. Now a PWHA can have a normal life, except that they have to take medicine. Being seropositive today you can do everything”.

In this chapter, I will describe the individual and socio-cultural factors influencing interaction in the families of people with HIV infection. I will present the themes

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6 See the special issue on AIDS of Social Science and Medicine 2000, 50(11).
which emerged during the extensive conversations with the informants of my research. Before describing the data, I would like to clarify some terms that I will be using in the following paragraphs. In my research, two types of family organisation are represented. One is that formed by parents and adult children in which either the PWHA never left the family of origin or he/she went back after a period of life outside the family. I have to note that mothers were very often the only parental figure present in the family. Other relatives can surround the nucleus of the family: grandparents, aunts and uncles are often named among the social network. The other type is formed by partners, married or not, with a stable relationship. In my sample the duration of the partnership ranged from seven up to fifteen years. For couples, with or without children, the relationships with other relatives are also part of the social life.

I will present data on the interactions with the ‘external world’, by which I intend the social network involved in the daily life of my informants. This includes neighbours, friends and work colleagues.

**THE FAMILY AS A GROUP OF INDIVIDUALS**

The family is a group of people in close relationship and each member participates in the family interactions with his or her individual characteristics. Any event affecting one individual has a repercussion on the entire family.

Social-demographic data are of relevant importance in that they affect the interaction that unfolds in the families interviewed. The most relevant data are summarised in the tables in Appendix 1.

I will discuss some of the themes that resulted of importance in the stories of my informants, as age, knowledge and illness experience about HIV infection, religious beliefs and attitude towards life after HIV infection disclosure.

Age can be of great importance when the care giving requires heavy physical activities as is often the case for people assisting PWHA in advanced stages of infection. All the interviewed PWHA were in good physical conditions during the
period of my research; therefore, the physical demand was currently not heavy on the caregivers. Also relevant to age differences are the expected roles that many feel corresponds to their ages, such as being a parent, a child or a spouse. I will discuss extensively how important are the roles in the family in shaping attitudes and meanings.

Knowledge of HIV infection also varied widely: basic information about modes of transmission reached all the informants. Therefore, nobody reported fears of contagion through daily activities. Some of the family members deepened their knowledge through specific readings and through the contacts with medical services, which in turn depended on the involvement in the medical follow up of the PWHA.

Three of the seven HIV positive informants had already experienced full-blown AIDS\(^7\). They recovered and now they perceive their actual health condition as a ‘regeneration’ of which they are surprised themselves. Other informants experienced ill-health because of minor ailments, mostly due to the side effects of the HAART. It is worth noting that minor ailments are often ascribed to health ‘weaknesses’, consistent with health problems in the past, before the infection. This explanation contributed in maintaining a sense of continuity with the past, preventing HIV from taking over every health related problem. The anthropological concept of ‘illness’, the individual own explanation about illness (Helman 1994:107) was becoming ‘alive’, while listening to the stories of my informants.

Religious beliefs proved to be very helpful in sickness and facilitated a “positive reappraisal” (Folkman 1997) of the distressing events. Only two of seven HIV positive subjects acknowledged to believe in God and to practise the Catholic religion. Many other informants, raised within Catholic education, either are non-

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\(^7\) Full Blown AIDS is the final stage of HIV infection, when the immune system is unable to keep under control a variety of infections that are for this reason called opportunistic. Symptoms, at this stage, vary according to the infections that develop: from dementia and other neurological deficiencies to cancer, blindness due to eye infection or gastrointestinal and respiratory symptoms. Often a general wasting can be observed, fever, lost of appetite and fatigue are prominent.
believers or do not practise - the latter being a common occurrence in Italy, where the Catholic religion, taught in schools and impinging our daily life, becomes a part of our cultural background. Two families made a vow and its fulfilment contributed to strengthen the belief in the power of faith and to reduce the sense of vulnerability.

“We are devoted to Santa Rita. We always have her images with us. We made an offering to her in the church and Luca also went to the sanctuary down in Umbria. He promised to offer her a silver heart when he was sick and he brought it there” (Luca’s mother).

“I don’t know if it was because of this [that Pamela recovered], but I promised God that I would go everyday to Mass, except if I were very busy with the children, has he helped Pamela to recover. That is what I do know, I go everyday, if I can” (Pamela’s mother).

Other informants reported positive insights from the Buddhist religion. Without being religious, they make use of some teachings of this religion to live more positively.

A final worthy note concerns the attitude of the PWHA towards his/her own experience and the influence this attitude has on the family as a whole. The attitude depends on each one’s personality, self-esteem, social support, experience of illness, perspective for the future and perception of HIV infection and has a strong influence on the day to day life within the family, which is greatly dependent on the well-being of the PWHA.

All but two PWHA said that they were lucky. At the beginning, this surprised me, but once interpreted in the context of the AIDS epidemic, ‘being lucky’ takes on another meaning. They feel lucky to have survived up to the time of the new therapies, or to have got the HIV infection in a period when it is not fatal anymore, lucky for having a body that is able to communicate what is good for it, lucky to have the support of the family, lucky and sometimes surprised to be alive.

**FAMILY INTERACTIONS**

**Disclosure**

The disclosure of the HIV test result is a very important moment in shaping the interactions of the family members and the management and the consequences of
Health staff in some cases managed the disclosure process very unethically. Two informants of seven had the test done without previous consent. In one case, the result was disclosed to the informant’s mother first. Both these cases happened after 1990 and they, together with the examples that I gave in the initial chapters, show how little the rights to informed consent and privacy are respected. The stigma attached to the infection hinders the prosecution of those who infringe the law. Furthermore, the fears about confidentiality stop the affected people from denouncing the offence (Agnoletto 2000).

Informants have been aware of their HIV infection for some time, with a range varying from 3 to 16 years. This makes their stories on disclosure a reconstruction of the past experience. The narratives they recounted to me are already the result of multiple rearrangements of this experience.

The reactions of the family to the HIV test result vary depending on different factors. The responses were partly determined by the moment in the history of AIDS epidemic and the available information about it. People found to be HIV positive in the earlier years of the epidemic, in the 80’s, report a low awareness about the significance of the infection:

“We knew about it at the real beginning, but we did not really know what it was. In fact, when she told me, I said - go on! What is this?- I could not imagine this was so severe. It was with the following information, the campaigns, that I realised it was something bad” (Pamela’s mother).

In the early 90’s, Italy was at the peak of the epidemic: mass-media focused on the great number of deaths related to HIV infection. In that period, an HIV positive result was immediately associated with suffering and dying. This idea was objectified when in the contact with the health services, where the image of AIDS was worn on the faces of the other positive people using the services. PWHA and their families could see the future in the bodies of those who were already sick.

After the introduction of the HAART, in 1997, and the change in the life
expectancy, the disclosure about a positive test became less traumatic and new issues have come forth. As is the case of this mother worried for the future of her child, not his death.

“I did not react well [to the HIV result]. I am afraid, I am getting old. Who will take care of him when I am not here anymore?” (Luca’s mother).

Another important factor in the family response to the HIV test result is the often inherent second disclosure of the behaviour responsible of the HIV transmission. This ‘double disclosure’ introduces another social problem such as drug abuse, and often becomes the immediate focus of attention. As Marianne put it:

“In a family, when something like this happens [a member who tests HIV positive], it is very difficult, because a positive test is bound to other problems. For some it is drug addiction, for others it is homosexuality”.

Often families of informants who have been involved in drug addiction have been more upset and shocked by knowing of drug use than of HIV infection. When I asked, in separate occasion, the mothers of Thomas, Pino and Pamela to talk about the experience of having an HIV positive child, they immediately switched the conversation to the disclosure of drug addiction.

Mothers’ role in Italy is still considered that of the nurturing of the children and they often consider their children’s drug addiction the result of their own failure as mothers.

“Still now it [her son’s addiction] is something I cannot explain…. I was so sure of Thomas, I had no problems with him… it is still unresolved for me. It was not so much the seropositivity, but when he told me of drug addiction it was a total shock. I couldn’t take it. I wanted to die. It was the end of everything. I am a mother who has always worried about my children, intelligent…enough and…maybe too anxious…. I was always here, I did not regret, I did it with great pleasure, I cannot explain it at all”. (Thomas’ mother)

Or when a mother tried to explain the cause of her child drug abuse:

“I don’t know why [she got into drug]. Many times I thought I did something wrong. Maybe, I don’t know what was the mistake” (Pamela’s mother)

Therefore, the test result is viewed as a confirmation of their failure, the objective and lasting proof of their faults and guilt (Foglia 1996).

“I feel different, because everybody had children and it worked out well, but I ….everybody, maybe unconsciously looks for guilt. They say….no they do not say, but they think - how is it that you did not realise? -” (Thomas’ mother)
While guilt is often faced by mothers, drug abuse findings have generated psychological theories relating addiction to the presence of an intrusive mother, as well as to an absent father. In 1999, at the congress of the Italian Society of Psychology, a research done in Milan was presented. Through the analysis of drug addicts’ family relations, the researchers concluded that the exclusion of the father from family management is rooted in a lack of a father-son relationship in the previous generation (Gruppo Abele 2000, 323). Although I could not verify this conclusion, I observed that in all the stories of drug addiction it was common for there to be a missing or rarely present father. They left the family, died or were just too busy with the work, considering that looking after children is not a man’s job.

“The only one always taking care of me was my mother. My father was old-fashioned. For him mothers should care for the children” (Pamela).

“My father? Yes, we got along well, he always said yes. My mother really was the one who educated me, my father…well during days he was working and in the evening, most of the times, he went out” (Pino)

In relation to this, it is interesting to note that only in Thomas’ family the father was part of the family. Nevertheless, Thomas requested me not to talk to his father and managed to send him away the day I visited the family.

The response to disclosure is different in couples: except for the case of Renato, all the other partners were informed about HIV infection before or immediately after getting involved in the relationship. Therefore the couple relationship is built around this awareness; the acceptance of the sero-difference is a pre-existing condition to the formation of the family. The case can be different for couples that formed before knowing the result of the test, as is the case for one of my informants. In this likelihood the reaction of the partner can be ambiguous. As described in the work of Castro (1998) about Mexican families, “solidarity and rejection can intersect”. The ambivalence is between the felt duty for the partner to remain with the infected person, because of love and solidarity, and rejection, due to fear of transmission and blame for the acquired infection.

“At the beginning I was so scared, I kept all his belongings apart from mine. It really took a long time to come to terms with it” (Renato’s wife)
Although in my research, I only considered people who were living with their families and partners who rejected the PWHA have not been included, cases of rejection are not uncommon. One doctor in charge of attending patients who come to the HIV services for the first time, explained to me that the disclosure process can take a long time and it is an important test for the relationship of couples. People found positive to the test are afraid to be rejected, even by the family and even more by partners. Couples have to deal with sexuality and the concern of possible contagion. Further in the chapter, I will return to the topic of couples and sexuality, based on the interviews I did with partners who remained with the PWHA.

I would like to make a short remark on the possible ‘double burden’ for women who are found positive. I already explained that in Italy HIV infection is frequently associated with moral judgement. Deviant sexuality or promiscuous relationships are blamed on PWHA. In the Italian context, where a ‘macho’ or chauvinistic mentality still prevails, women have to bear the double burden of HIV infection and of the stigma of ‘immorality’. If multiple relations are accepted and even prized for men, for women they are stigmatising and the reason for moral rejection.

“Women many times told me that they are treated as prostitutes when they communicate about their infection. It is not allowed or forgiven for a woman to have a casual relationship. Even if they got the infection from their usual partner they are blamed” (a doctor in charge of first contact with health service for PWHA).

As described in the article by Lawless et al. (1996) “the messages are so powerful and insidious that it is difficult for women not to appropriate them”. In fact, one of the informants, who was infected through a heterosexual contact, felt the need to explain her infection like this:

“I only had two ‘adventures’ in my life and one with someone I knew. I did not have a loose life. I did not look for it [HIV infection]”.

Finally, I would like to discuss a recurrent metaphor used by PWHA or family members to describe the event of disclosure of a positive test. Three out of seven described the event as a *tegolata*, to be hit by a tile on the head. This metaphor is used when something painful and unexpected happens. In fact, despite the
Acknowledgement of risky behaviour, many informants referred to testing positive for HIV as an unexpected result.

“I did not take any precautions to avoid it [HIV], but sincerely I did not expect this result. I felt like I was out of it [drug addiction]; therefore, it came like a punishment. It was not fair” (Ugo).

**Information management**

Once members of the family, one or more, are aware of the HIV infection, the process of information management begins. This involves a complex strategy of deciding who should know and how to inform other people. This disclosure process follows some rules that are bargained for within the family. The main voice in the negotiation is that of the PWHA, but each member tend to have a key confidant to whom to address in moments of emotional turmoil.

The result of the test is communicated to those who are supposed to understand, to be non-judgmental and supportive.

“We said that to people that we considered ready to understand, because of their cultural background or life experience. If you choose the people to inform, possibly you will have a positive reaction” (Clara’s husband).

Sometimes disclosure to other people is made out of a need to receive support to face a worsening situation.

“Ugo’s illness gave us the incentive to tell our sons about HIV infection and Ugo’s history of drug addiction...we were always waiting, considering them too young; we didn’t know how to tell them” (Ugo’s wife).

Other times the information about HIV is withheld to spare worry and to avoid alarm to others. Usually distant relatives or even parents (in the case of couples), as well as friends.

Informants cite a great fear of disclosure in the work place. Only one informed his employer. The unenforced law that should guarantee against discrimination does not give people the assurance either to maintain their job, or to avoid stigmatisation. Therefore, the choice is normally to keep it secret and to take a day off or make different excuses to go for a medical check up. The issue of non-disclosure in the workplace becomes particularly a problem due to the management of the HAART. This, on the one hand, helps in regaining health, promoting the desire to be
reintegrated in the job market expressed by some PWHA. But, on the other hand, the management of the HAART, which sometimes requires intake during the working hours, becomes inconvenient if done in secrecy.

None of my informants decided to ‘go public’, mostly because of fear of rejection and stigmatisation. The concealment of HIV infection helps in maintaining the stigma and the public image of the disease. Cases that become public are just those manipulated by the media, which look for sensationalistic news, twisting the stories of PWHA to make them more attractive to the public. As one key informant, Marianne, who decided to go public, said:

“Now I declare it - my son is positive - because I want people to learn to accept AIDS as they do for other diseases. Italy is very closed on this [she is of French origin], people turn their heads. Until we keep on concealing, it will never change” (Marianne).

Communication within the family as well as with the external world becomes a major issue and information management takes up much of the family’s energies. Some PWHA share all the information regarding their health status with the family, while others provide such information on a need-only basis in order to keep the family out of their health related matters.

“It is very hard for me to know things about his health. I don’t know about it. Doctors don’t want to tell me. Thomas doesn’t want to let me know” (Thomas’ mother).

Parents seem to suffer about being excluded, while partners take it more as a choice not to dedicate too much attention to matters related to the illness.

“We do not dedicate time to this [HIV], better said, we do not dedicate any time to it. We talk about it only if there is something important or new to say” (Clara’s husband).

The communication with the external world plays a role in shaping the social network of PWHA and their families. Even if many of the previous social relations are maintained over time, a special bond is felt with those who are aware of the HIV infection. In most of the cases, these relationships have a positive impact on the emotional life of the family, providing support and solace in difficult moments and a locus for confidential and open talks.

“I feel at ease with my neighbours. They know all of what happens, but they do not drag up the past. They are solidly behind me and ask about Pino. They are close to me when I need them” (Pino’s mother).
The limitations imposed on communication by the fear of stigma and discrimination is sometimes experienced as distressful, preventing the establishment of an open relationship and of a ‘normal’ life.

“At work I have some acquaintances, but they do not know about me. This annoys me: living with this secret makes me feel different from the others. I cannot talk freely, I always need to hide a part of my life” (Ugo).

The ‘felt stigma’, the socially discreditable experience of living with HIV/AIDS, may hinder the relations with the external world, with a contraction of social life.

“I am not able to be in contact with people anymore, I’m not up to it now” (Thomas’ mother).

It is interesting to note that even in the conversations with me, the words HIV and AIDS were seldom spoken. ‘This thing’, ‘it’, ‘the disease’, ‘the infection’ substitute the dreadful words. This attitude underscores the power of language and words. When something causing suffering is not said, it does not really exist. The use of neutral words helps in dealing with an unpleasant reality.

**Adjustment**

Once the disclosure process within the family has taken place, the adaptation to the new situation begins. From this will depend the organisation of everyday life and its dynamic. HIV infection has very peculiar features, its presence is often silent, with a latent period that can last a long time, in which no signs of illness are present. At the same time, the presence of HIV, even silent, can have the disruptive force of an invalidating illness. It is in fact the perception of this presence that shapes attitudes and practices in everyday life.

In their study on management of everyday life, Pantzou and others (1998) distinguish three major tendencies: one is negative, “AIDS comes and interrupts a life course”. One is positive, “AIDS comes to interrupt, change and sometimes improve a way of life” and a third neutral one, “AIDS comes but life is continuing with no important change”. 
In my research, in the narratives of the informants, I also found those attitudes, both in PWHA and in the family members. However, I will argue that the most adaptive response in the era of combination therapy corresponds to the third tendency. In this case no space is left for HIV to alter the life trajectory and the identity of the family, neither in a positive nor in a negative way (see argumentation in next chapter). Anyway, these attitudes are not static because they can change over time, following life events. The three tendencies are illustrated by the cases of some informants.

Thomas’ family, when I met them, belongs to the first group. However, interestingly, the disruptive force of HIV infection did not manifest itself with the disclosure of the test result. During that period, the family was struggling against drug addiction. It was some years after, when Thomas started the antiretroviral therapies and saw his body becoming the image of illness, that the disruptive event took place. Life course was interrupted and expectations about the future shattered. His attitude about HIV infection and that of the family changed.

Luca’s mother belongs to the second group, with a somewhat positive outlook. Luca’s positive test result came as a tegolata; she was in a depressive mood for some time, but she quickly reacted and now she came to terms with the new situation. In fact, she believes that the infection experience has improved the family relation.

“Yes, sometimes I forget about it, maybe because Luca himself forget about it. Sometimes I even think it is not true. He is so active and helps me more than before. After this experience we are more united than before”.

Pamela and Ugo belong to the third and neutral outlook group. Both of them were found positive for the HIV test in the very early period of the epidemic. Their reactions were similar: they did not attend medical services, refused all therapies and went on with their life, forgetting about HIV. They found partners who accepted them and continued their life ‘trajectories’ together. Even the experience of severe illness did not alter their life plans.

But what determines these different responses?
The expectations projected by family members onto the family relationships are an important factor in determining the response. These expectations differ for parents and partners. Parents expressed concern mostly about the well being of their children. After disclosure, they gave up their own expectations about life and therefore became more dependent on the reactions of their HIV positive son or daughter.

“I am happy if he is happy. When Thomas feels bad I would like to withdraw into my shell” (Thomas’ mother)

Partners who willingly decided to stay with the PWHA, look for personal fulfilment in strengthening their family bond. They demand the realisation of a common project, especially now that in spite of the HIV infection, such plan results possible. I will give some examples on the basis of my fieldwork: when Pamela decided to return to her studies, her husband was very disappointed. He felt that Pamela’s decision was due to a lack of satisfaction in her family life.

“For me this means she is not happy in caring for her husband and family, in taking care of the house”.

In another case, when Renato decided he did not want to see friends and go out so often, his wife complained. She saw it as a downgrading of their social relations.

For couples, another important issue is at stake: sexual life. All couples, except the case in which HIV was discovered after the marriage, suggested they had a satisfactory sexual life. Delor (1998) reviewed the available literature about PWHA sexuality and risk taking. He pointed out two major categories to explain the determinants of sexuality of PWHA: the first one considering determinants within the individual, the other one focusing on the contextual and interactional processes. However, the limitation of the studies he considered is their focus on risk taking, forgetting “the affective and social dimensions of the sexual relationship”. Delors (1998) proposes a new approach to study sexuality, in which sexual interactions is interpreted as a “identity building work” reflecting the quest for social integration with objective (structural) and subjective (symbolic) significance.

Two couples out of four were having sex without protection and conceived children
during their relationships. All the children are negative. Both these couples have a long-standing relationship, 15 and 11 years. It is interesting to note that each of these informants gave his/her own version about sexual activities in terms of frequency of intercourse and use of condom: women reported inconstant use while men said they never use. Two couples reported constant use of condom; one is cautiously abandoning condom use to have a child. All the partners I interviewed were still negative as of the last HIV test performed. Only in one case, did the partner always refuse to have an HIV test.

The seronegative partners in couples having unprotected sex declared no fear of contagion, and stressed during the interview their total acceptance of the other. This attitude reflects what Delor (1998) describe as a process of “protecting an ideal other”, in which negative partners are in fact defending the values attributed to the relationship and to their role. The decision to practise unprotected sex stems from the underplaying of the disrupting experience and represents a stance to maintain the family identity.

In my discussions with the doctors of the HIV clinic, I was told many times about what they defined as an “epidemic of pregnancies”. Dr. Nozza, one of my key informants:

“What HIV positive people really need now is to have a normal family. This is what they want, without the limitations due to HIV infection. Therefore, they want to have sexual intercourse with negative people as well. They want to have children, to build up a family”.

The regained health status and the regenerated perspectives for the future are re-affirmed through a ‘long-term project’ as that of a child. Of the four couples in my sample, one woman was two months pregnant and another one was starting the attempt to become pregnant.

“Yes, now we want a child. Time has smoothened my suffering. Before it was obvious, I could not have a child, but lately… I talked with my doctor, my situation is good, there are no problems, we have to take advantage of the situation” (Clara)

PWHA and their families have experienced the death of many people around them. Especially for persons involved in drug addiction and for those who have been living with HIV for a number of years, it is common to have witnessed to the
The extensive demise of friends and acquaintances. Often family members have participated in the bereavement of their children or spouses and shared the sufferings and the fears about uncertainty that these experiences stir up. These experiences had a strong effect on the illness perception and contribute to forge the image of a PWHA as a survivor.

The term ‘survivor’, described in the literature regarding the survivors of the Nazi camps, has been proposed as a “way of thinking about the experience of groups most affected by AIDS epidemic” (Wright 1998). Some PWHA I interviewed did indeed express this feeling.

“It is difficult to understand what being HIV positive means. My moodiness, my sadness. To me, it is like having been in the Vietnam War. I am a survivor, like having been in a Lager. You feel different. Why did I not die? While I have so many friends who died” (Thomas).

For some PWHA this feeling became cause of distress (Wright 1998). Others managed to construct a “theory on the meaning of their diagnosis and long-term survival” (Crossley 1997), which allowed them to re-elaborate the traumatic experience and to control their feelings of vulnerability.

A similar process is at work in the group of family members. They interpreted the exceptionality of their beloved ascribing it to some special characteristics. Attributing them exceptional features, that make them different from the other PWHA, family members construct a ‘lay theory’ which justifies the survival and is used to cope with uncertainty. HIV infection can cause illness at any moment: to have special characteristics which make less vulnerable is perceived as a defence against randomness.

“He is a monster. His doctor also says so. It is amazing the way he can swallow all this pills without any problem. He can take ten pills at a time” (Ugo’s wife)
“He is reacting well. Many of his friends, whom I met, have died. He must be an exception” (Pino’s mother).

Conclusions
Families respond to HIV infection dynamically, adjusting to intervening factors. In this chapter, I described some of these factors and their interrelations.
Living in a context where HIV infection is stigmatised, PWHA and their families have to adjust to a complicated situation in which their individual as well as their family identity is assaulted.

The disclosure process is a very delicate moment in the life of the family and its management, influenced by previous familial relationships, has critical effects on the following events. The reactions of family members reflect their position in the family structure and depend from each one’s role within the family and in the society.

Mothers tend to have feelings of guilt associated with their children HIV infection. This attitude often causes the perception of HIV infection as a strain in their identity, making more difficult the process of adaptation.

Spouses, who built their family identity around the awareness about HIV infection, met fewer difficulties in adjusting to it. The case of couples in which HIV infection was found only after the formation of the family can be different. In my sample, only one couple lived this event and they seemed to have had a longer and more difficult time in adapting to the new situation.

HIV infection and AIDS are associated with stigma, illness and death, which make living with HIV infection a difficult experience. PWHA and their families developed strategies to manage the fears, the uncertainty and the distress associated with the diagnosis of HIV infection. The recently introduced combination therapy provided new perspectives for PWHA and those around them, as I will discuss later, but the fearful image of the disease is maintained by social representations and past experiences.

To cope with stigma and uncertainty family members found different strategies. Religious beliefs, construction of models of exceptionality, management of information, long-term projects (as having a child) and preservation of family...
identity are some themes that emerged from the conversations with the informants of my research.

8 See a recent serial of articles appeared in newspaper in occasion of the World Aids Congress in Durban, South Africa (La Repubblica June-July 2000).
5. THE THERAPIES AND THE FUTURE

All along, I have been stressing how the HAART has changed the history of the AIDS epidemic in the countries that can afford to provide it. I have explained the problems concerning the management of the HAART and presented the medical discourse on it. In this chapter, I will discuss the new therapies from the point of view of the people who daily have to ‘swallow’ the numerous pills and of those around them.

Taking the therapies

The HAART regimens are not easy to manage. Strict schedules, multiple administrations with detailed directions about timing and collateral necessities to increase absorption or to reduce side effects (administration on an empty stomach or after fatty meals and intake of fluids) greatly complicate the combination therapies. Nowadays, around 15 different compounds are available which allow the selection of the most suitable combination with respect to tolerability, efficacy and easiness of management.

The combination treatments require maximal adherence. Less than optimal adherence may result in the loss of efficacy of the treatment due to the selection of resistant viral strains. Cross-resistance among molecules of the same family can compromise future treatment options; therefore, it becomes critical in the management of the combination regimens to maintain high motivation for adherence.

Many studies on compliance revealed the direct association of non-adherence to the complexity of the regimen, the amount of medications to be taken and the interference on daily life. Knowledge and beliefs about the efficacy of the medication and support from others: health staff, family and friends are also important factors in maintaining adherence (Chesney et al. 2000).

“The first things they [people coming to HIV service for the first time] always ask about the therapy are how many pills will they have to swallow, how is the schedule and if it will change their daily life. What they want is to take it only twice a day, not to have to take pills during the afternoon when they work” (Dr. Nozza).
Strategies to address adherence include a careful explanation about the administration schedules, of side effects and of the importance of compliance. These in turn depend on efficient communication and dialogue between doctor and patient. Monitoring of side effects and prompt response to their occurrence can also increase the likelihood of successful adherence.

All the PWHA included in my research are taking combination therapies; some of them had been previously taking AZT or ddI. Nearly all of them have been through more than one regimen, but finally found a suitable combination. I was surprised by their technical knowledge: the internalisation of the medical discourse about virological and immunological notions is complete. All of them are highly aware about the available therapeutic choices, the probability of disease progression and the developments of pharmacological research.

Therapies mark the time in a significant way for the PWHA who have to invest great effort in getting into the habit of taking the pills. Forgetfulness is the most reported cause of lost doses. Correspondence of intake with the meals resulted successful in overcoming the lapses of memory. To adhere to the therapy also means to be reminded twice or trice a day about HIV infection and dependency from the therapy.

"Now I take 14 pills a day. It is better compared to the past, but still it is very annoying. Every time you take them, you are reminded about it [HIV]. Some nights they get stuck in my throat. It is very difficult to swallow them" (Pamela).

The knowledge by family members about the HAART varied with the involvement in the health management of the PWHA. All of them showed confidence in the effectiveness of the new therapies, but expressed their hopes for a long-term solution which would spare their beloved the dependency from the medicine.

"With these treatment they can survive…yes, more than 20 years. Medicines are effective: there was a period in which his viral load was down to zero. He had no virus around. We follow the news, there are new forms of medicine. Soon there will be a vaccine" (Luca’s mother).

Normally the practical management of the treatment is left with the PWHA, while the family supports him or her with the necessary flexibility in daily arrangements and the psychological support.
“He had to change regimens a few times, but now it is OK. Within the family, with my children, we call the medicine Viagra (popular drug to increase sexual performances), because there are blue pills. My son says - mamma, do not worry, one day it will be effective [for sexual potency] -. We make jokes about it, but I see that he is doing fine” (Ugo’s wife).

The family oversees the adherence to the regimen.

“He does not take care of himself, but I noticed that he takes all the medicine. He says he wants to die, but he is afraid of getting sick and swallows all the pills regularly” (Thomas’ mother).

“Yes, he stopped for 15 days [the therapy]. His stupid brother told him he could heal himself with positive energies, but we saw the results, when he had the blood tests: his values (viral load and immune cells) were a disaster. He immediately started the regimen again” (Ugo’s wife).

In general, the families said that nowadays the therapies are more manageable compared with the past. Among the most lamented side effects, gastric discomfort and diarrhoea are prominent. However, the most influential in determining the acceptance or rejection of the treatment is the lipodistrophy. This changes the body shape by a fat redistribution, causing a reduction in the subcutaneous fat layers in the limbs and in the cheeks. The fat mass covering the cheekbones disappears and the limbs become stick-like.

“This [lipodistrophy] is one of the main reasons for quitting the therapy. The mechanism is not yet known, and even the responsible compound is not defined yet. Women especially are refusing the therapies” (Dr. Massimo).

Once the suitable regimen is found, the therapy should be taken forever; however, intermittent regimens are under study to reduce the costs for the medical services and the strain for PWHA.

Informants seemed convinced about the efficacy of the treatment, but another important variable in the attitude towards the therapy rests in the doctor-patient relation and its perception by the PWHA and his/her family. I was impressed by the satisfaction of the people I interviewed about the health services, at least for what concerns the HIV clinic. Everybody expressed satisfaction about doctors and nurses working there and the organisation of the services. It is possible that my known position as an ex-worker in that same structure influenced what people told me, but the narratives about their contacts with the health services were definitely positive.

“She always found very helpful people, who followed her carefully. I am happy
we found specialised staff who can tell us what to do and what not to do, who are there when we need them” (Clara’s husband).
“I was attending another clinic before. Then I came here and it has been good since the beginning. They shifted Massimo onto me and now I don’t want to change. We have a very trusting relationship” (Pamela).

Care giving and the time

But what is the impact of HAART on family relationships and on the care giving? To answer this question I will have to revise the concept of care giving, by which I mean all the range of activities, at a practical and psychological level, to support the well-being of an individual. In this definition, the central role is attributed to the receiver of care, whose well-being has to be addressed. Nevertheless, the interactional character of care giving impinges upon taking into consideration the role played by those who provide the assistance and to the context around them. I will describe the most notable change in perspective and needs and discuss the response of the family to it.

It is widely accepted that the HAART is having a profound impact on life expectancy of HIV infected people. Living with HIV infection does not imply terminality anymore. This change in time perspective is having a profound effect on the temporal orientation of PWHA.

In a recent paper, Davies (1997) analysed the different forms of temporal orientation adopted by PWHA to adjust to the uncertainty about the future. In her study, done among PWHA who were not on HAART, the author defined three categories of time orientation: “living with a philosophy of the present”, “living in the future” and “living in the empty present”, each one corresponding to a “stance towards the HIV diagnosis”. I will use one of her categories to describe the current situation of PWHA on combination therapy in Italy. Through the interviews, it became clear that most of the HIV positive informants are actually “living in the future”: their stance is to refuse the possibility of an imminent death and therefore they prevent HIV infection from influencing their plans for the future.

“I see a happy future. I think at when I will retire and I will live with my partner in a country-house in Tuscany. I will decorate the villa of some rich Englishman, just for the fun of it” (Luca).
Due to this important change in time perspective, the current needs of PWHA concern ‘normalisation’. They want to lead a ‘normal life’ (Pierret 2000).

“Sometimes I feel…not really useless, but I feel I could do something. In the morning, when I am in bed, I here people going to work. I feel some kind of regret for not having a role” (Pino).

The caregivers are adapting to this new demand at a different pace.

In the family, reciprocal relations and their changes over time determine the forms of providing care. As discussed in the previous chapters, parental and conjugal roles are central in the construction and organisation of family life.

Parents, mostly mothers, are responsible for the ‘production’ of healthy and successful children and the failure of this goal is source of personal distress and social strain. HIV infection, tightly associated with social stigmatisation, can interrupt the trajectory of the parents.

“What a parent feels is different [from partners]. Of course, what happened to Thomas influenced our life as parents. I don’t exactly know how to explain, but we are less willing…to live; our interests have been reduced” (Thomas’ mother).

Mothers, upset by this change in life plan and by the experience of uncertainty associated with HIV infection, live in another time perspective. This is more close to “living in the empty present”, where the ability to project into the future is shattered by the trauma of HIV infection (Davies 1997). Therefore, they are finding it more difficult to adapt to the change in perspective and the quest for normality of their children living with HIV.

“I am living with the Damocle’s sword [metaphor to express uncertainty about perceived danger]. I am always thinking about it. Now things are going fine, but may not always be like this. When you are seropositive, you remain seropositive. I cannot forget it” (Pamela’s mother).

An explanation of this attitude is to be found in the role of the mothers in the Italian family. Mothers, who by care giving re-held their nurturing role, find it difficult to assume a more distanced parental role. The disruption in their life trajectories brought about by HIV infection, caused an inability to project their role into the future, therefore they tend to maintain their nurturing role, which provide them with
some sense of control over uncertainty.

“Our perspectives for the future? My house is his house. I will never throw him out. I just hope I die before him” (Pino’s mother).

The case of Marianne, who went public, overcoming the perceived strain in familial expectations, illustrates adequately how the shift in the maternal role helped in the response to the new needs or even anticipated them.

“I had always helped him financially, but at a certain moment, advised by a friend in the association [ASA], I told him he had to manage by himself. It was a tremendous effort for me, but it worked. He took his life in his own hands”.

In fact, the difficult adaptation of mothers to the new perspective of future does not foster the full realisation of the life plan of their children. The children lamented difficulties in facing the normality of the others or the lack of a role in the society, which will enable them to go back into their future.

Partners who chose to share the experience of living with HIV, integrated this event in their life trajectories. Since the beginning, they have learned to minimise the impact of HIV on their plans. The advent of HAART re-established the possibilities of continuity and re-awoke the hope in a complete fulfilment of the conjugal role.

Care giving by partners is now identified with the accomplishment of the conjugal roles, which in Italy are quite strongly defined. Even if the participation of women in the job market has been increasing in the last fifty years, with more flexibility in the family roles, women are still considered in charge of the welfare of the of the household. Therefore, women are held responsible for taking care of the household chores and for keeping the family unite. Men, whose main task is the ‘bread-winning’, are in charge of the economic solidity of the family and should represent the authoritative voice within the family. Nowadays, these roles are beginning to be shared between partners, but in general, cultural expectations are maintained.

The conjugal union, even if not formalised through marriage, implies the agreement on a common plan for the future, which is often confirmed through reproduction. Having children allows for the social recognition as a family, essersi sistemati, “the
primary goal in life of any married couple” (Pitkin 1985).

The demand of ‘normality’ is satisfied through the fulfilment of the established roles. As is exemplified in the stories of the informants of my study, partners of PWHA maintained their roles in face of HIV infection and demand the same effort to their partners.

**Conclusions**

In this chapter, I presented the issues concerning the combination therapy from the point of view of the informants: PWHA and their caregivers.

I discussed how PWHA and their families internalised the medical discourse on the HAART and its effects and I presented some of the major constrains in dealing with the treatment.

In discussing the impact of the new therapy on the care giving, I presented the important change which took place in the time orientation of PWHA. The possibility of a future is impinging the daily life of PWHA. They want to have a normal life, in which they can realise their plans.

The impact of HIV on the life trajectory of each member of the family has a profound influence on the ability to adjust to the change in perspective of PWHA. Mothers, whose identity was spoiled by this experience and who, through care giving, regained a sense of control, find it more difficult to adapt to the demand of normality of their children. This delay in adaptation increase their suffering and hinders the empowerment of their positive child. Partners seemed to be adapting faster to the renewed perspectives for the future. This was especially true for those who since the beginning have been minimising the impact of HIV infection on their life plan.
AIDS history began with the notification of few cases of a rare disease in a group of homosexual men in the United States. From then on, an enormous amount of efforts has been invested in understanding and controlling its course.

Due to the powerlessness of clinical medicine in facing the fatal effects of HIV infection, for many years the basis of its management have rested in prevention and care. Families have been deeply involved in the informal care for PWHA and responded in different ways to the multiple needs of their HIV positive member.

The biographical disruption caused by a chronic illness is burdened, in the case of HIV infection, by the social stigma attached to it. The initial construction of AIDS as a sexually transmitted disease affecting the ‘deviants’, those whose behaviour fell out of the dominant models, did not lose its powerful effect over time. Even after twenty years from its acknowledgement and the numerous information campaigns, HIV infection is often experienced in concealment and secrecy, for fear of stigma and discrimination. This attitude, together with the fatal outcome of the infection, contributes to the disrupting effect of an HIV diagnosis.

Due to the social image of AIDS as a discreditable disease, the presence of HIV infection brings disruption not only to the HIV positive subjects, but also to those around them. The reaction to such an event is an ongoing process which determines changing attitudes and behaviours at an individual and interactional level.

The aim of my study was to describe the response of the family living with an HIV positive member. Therefore, the family was taken as a unit of analysis and care giving as a focus for analysis. I chose this approach to lay emphasis on familial relationships and highlight the social and cultural factors at stake in shaping the response to HIV infection in the family.

I interviewed PWHA and their main caregivers. I tried to grasp from their stories the meanings of the experience they were facing. I collected stories of suffering,
and illness, stories of shame and despair, but also stories of children growing, bills to pay and future to construct. The enormous heterogeneity was exciting and confusing.

To make the research more interesting, there was the recent introduction of the combination therapy that was changing the history of AIDS epidemic, transforming a fatal illness in a chronic condition. The therapeutic cocktails, with their numerous pills and burdensome side effects, did indeed ameliorated the health conditions of some of the PWHA, giving them the opportunity to think to a future.

It was important to understand what was going on in the family after the introduction of the combination therapy, in order to document the issues at stake and outline a picture of the situation in the current period.

Italy is, in Europe, among the mostly affected countries by HIV infection which spread first among people using intravenous drug and reached later the general population through sexual contacts. The involvement of IVDU supported the public image of AIDS as a disease of the ‘marginalised’ groups, fostering the attitude of blaming the victim for their own HIV infection. The position of the Catholic church and the late response by public health authorities contributed to the marginalisation of the affected population.

Italian family, embedded in a context of public stigmatisation and lack of assistance, turned to its own resources to face the situation. Roles in the family and internal relationships decided the distribution of tasks and responsibilities. The social network, carefully selected, provided the necessary support for practical and psychological assistance. Different strategies were adopted to cope with the feelings of uncertainty and with stigma.

Within my group of informants, I have found that stigma is still managed by PWHA and their families through concealment and careful information management, which takes up much of the family’s energies. This strategy of concealment is still very much a part of living with HIV in northern Italy.
Uncertainty, even in the face of a regained future, is very much an issue in the illness experience. I discussed some of the strategies used by PWHA and their caregivers to deal with this feeling.

Now, in the era of combination therapy, PWHA demand support for being re-integrated into a ‘normal’ life and family members respond to this quest at a different pace. Mothers who through care giving reconstructed their interrupted life plans by reverting to the nurturing role, which gave them a sense of control, are experiencing more difficulties in adapting to the new time perspective of their HIV positive children.

The attitude of spouses varies in dependence of the expectations they had from the couple relationship. Spouses who did not allow HIV presence to spoil their life trajectories, but rearranged it so as to minimise its impact on their plans for the future, are now facilitated in adjusting to the new demand of their HIV positive partner.

The situation can be different for couples that were established before the disclosure of the HIV infection, in which the planned trajectory did not include the ‘discredible’ experience of living with HIV. Unfortunately, the limitation of my research sample did not allow for further analysis of this possibility.

Conclusively, from the data I collected through my fieldwork I would like to suggest that, as for other chronic illness, the adjustment to an HIV positive diagnosis depends very much from the effect that this has on the individual’s identity. This, in turn, is shaped by the social interaction of the individual identity. In the northern Italian context, specifically in the city of Milan, and in what concern family care giving, familiar roles and consequent life plans have a great influence in the response to a stigmatised condition such as HIV infection.

These conclusions should be taken into consideration when external support is requested, in counselling and medical settings. The quest for normality of PWHA,
growing stronger with the new possibilities for the future awakened by the HAART, should be supported through the careful analysis of familial interaction. Special attention is needed for mothers, who have to find a new role within the family, where the nurturing relationship can be transformed into a more balanced relationship of mutual confidence and reciprocal support. The aim of the intervention should be targeted to the trajectory reconstruction and to the reduction of feelings of guilt and failure.

Another issue to address in the public and private arena and that is worth of future research is the paternal role. In my sample fathers’ perspectives were not represented. This is not a case, but a fact that can be addressed through the reconsideration of parental roles and gender issues. The social and medical services can foster a greater involvement of fathers in care giving and support of HIV positive children.

It is also evident for my conclusions that more efforts should be direct to the fight against the stigma associated with HIV infection. The growing mobilisation of HIV positive people can do a lot in this direction, but institutional support and mass-media participation is necessary to strengthen the message.
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