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MENTAL HEALTH CARE IN SERVICES SPECIALIZED IN STDs AND AIDS

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Introduction

AIDS, understood as a chronic disease, presents healthcare professionals with challenges that go beyond policies designed merely to control the epidemic and which have increased the need to ensure universal, equal and integral access to treatment.

The achievement of access to treatment and expansion of the provision of HIV testing and diagnosis have made it possible to reduce vertical transmission rates of the virus, decrease morbimortality, and increase life expectancy for people living with HIV/AIDS (PLWHA). As a result, as we observe their history, the public health policies of the Department of STDs, AIDS and Viral Hepatitis can be seen to advocate the improvement of the quality of life of the HIV-positive population. Among the many issues to be addressed based on this principle, there is also the need to consider the quality of mental health care.

The present work, titled *Mental Health Care in STDs/AIDS Specialized Services*, was developed by the Department of STDs, AIDS and Viral Hepatitis with the collaboration of a work group comprising researchers, healthcare professionals and representatives from civil society. It presents guidance for Specialized Healthcare Service (SHS) teams on mental health care and on possible ways to take up these patients in the Networks of Health Assistance through interfacing with other healthcare centers. These reflections are critical for improving the quality of healthcare services in this area.

This document was conceived from the need for SAS's multi-professional teams to take ownership of the construction process and/or to improve the mental health care model so that it would permit the active participation of all team professionals, while constructing relationships with other services and enhancing the quality of the integral assistance offered.

The chapters address mental health issues related to dimensions of living with HIV/AIDS, subjectivities of healthcare in HIV/AIDS services, healthcare strategies, psychological problems and mental disorders, the possibilities of integral assistance, building healthcare teams, and the challenge of insertion into the National Health Care Networks.

We hope this material is a starting point for team enlightenment and that it promotes reflections on mental health care.

Department of STDs, AIDS and Viral Hepatitis
Health Surveillance Secretariat
Brazilian Ministry of Health

Chapter 1

Mental health and dimensions of living with HIV/AIDS

Illustration: Mascarenhas

This chapter highlights some of the conceptual and historic aspects of the significance of the HIV/AIDS epidemic and discusses its social and inter-subjective impacts on Brazilian society, as well as how these impacts have created both a need for specialized psycho-social assistance for people living with HIV/AIDS (PLWHA[1]) and a need to enable public health service professionals to provide this care.

Progress in therapeutic and drug treatments now available to PLWHA is apparent and has brought significant improvements to their quality of life.

Note, however, that while there has been progress in the profile of the epidemic, it has not been possible to deconstruct prejudices related to the groups at risk that are mediated by perceptions and ethical, moral and religious beliefs based on out-of-date perceptions of the disease that were associated with its pathogenic nature (due to its viral transmission) and the socio-demographic characteristics of more vulnerable populations.

PLWHA are exposed to factors that can lead to psychological problems and mental disorders. On the one hand, there is the challenge of knowing that they are infected with a virus that is difficult to treat and has no cure in sight, either in the short or long term, and on the other hand, and equally important, having to deal on a daily basis with prejudice and social, sexual and affective discrimination.

These mental problems and disorders are reported by users of healthcare services and are observed in the routine practice of healthcare professionals; they represent new challenges for the integral, universal and equitable services advocated by the Brazilian Public Health System (*Sistema Único de Saúde*, referred to as simply "SUS").

1.1 The reality of people living with HIV/AIDS

Because it [AIDS] is a sexually transmitted disease, various myths arose related to its contagiousness, certainly as a result of the mystery and fear that are caused by ignorance of sexuality. AIDS carries with it the stigmas that already set apart those who are marginalized and

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[1] It is important to view those affected by AIDS as people who have rights; thus, the term "people living with HIV/AIDS" (PLWHA) has been a name of unity that is in harmony with the notion of solidarity.

discriminated against, such as homosexuals and drug users. All of this pushes a person down a clandestine path. In addition to being affected by a grave disease, having to live with it alone and hiding it is the worst tragedy that may befall an individual with AIDS (Daniel, 1994, p. 11).

In spite of all the scientific knowledge now known about this disease, the universal access to treatment provided, and the social benefits being made available, PLWHA still suffer discrimination from their families, social groups and support services. As a result of the difficulties in starting new affective, social, and sexual relationships, many PLWHA isolate themselves; they also face difficulties in making public their serological status due to their fear of rejection. Those who are able to find the self-motivation to resume their life projects often experience vulnerability, conflicts and embarrassing situations, as well as a disregard for their civil rights.

These situations and conditions may lead to feelings of low self-esteem, of not belonging, and of losing one's social and psychological identity, all of which may trigger psychological problems and mental disorders.

Healthcare teams are not always prepared to offer comprehensive and specialized care in outpatient facilities or referral services to PLWHA or to people presenting psychological problems and/or mental disorders.

Comprehending the other in all his/her multi-dimensionality is crucial to the development and effectiveness of integral care both from the perspective of prevention and from that of therapeutic regimen design. It is necessary to take into consideration the other's life history, his/her ability to choose and make decisions, experiences of sexuality, and sexual and reproductive rights, without losing sight of the possibility to enhance their competencies in order to reduce their vulnerabilities and promote a better quality of life. In addition to giving appropriate attention to the context of vulnerabilities and the available resources, and equally to values and beliefs, there is also a need to strengthen the dialog between healthcare service providers and users. Language differentiates us; it is through words that we are able to define our place in the world, to represent our body and to reinvent reality.

Conversation – understood as a soft technology and a tool of the trade in healthcare – is a powerful resource available to users and providers, which can help them to organize themselves and others. Opportunities to get together and converse may help individuals to assign new meanings to the disease and to develop ways to deal with loss, as well as to adapt themselves to treatment in a manner compatible with their individual lifestyles.

Sontag (1989, p. 21) states that:

> "The metaphorical genealogy of AIDS is two-fold. As a micro-process, it is seen as similar to cancer: an invasion. When the focus is on the transmission of the disease, an older metaphor comes to mind, which reminds people of syphilis: pollution."

In both of these processes, AIDS is still viewed as a mystery, acutely feared and deeply internalized as morally contagious, pathogenic and incurable; consequently, these attitudes result in expressions of rejection and aggression and the social exclusion of infected and affected individuals.

Caring for PLWHA requires expanding assistance beyond providing individual attention in healthcare centers: it also requires the inclusion of their social networks and groups in order to increase both methods of fighting the disease and adherence to treatment. This (re)organization presupposes a review of concepts, attitudes and procedures, with an emphasis on discussions throughout the process of restructuring the lifestyles of persons assisted.

In order to contribute to the reflections and issues raised here, we present some of the dimensions and challenges necessary for better understanding these realities. We then suggest guidelines and strategies for facing these issues that may be taken into consideration by healthcare teams and services.

1.2 Biomedical and clinical dimensions

AIDS became a disease that had the potential to be controlled upon the advent of combined antiretroviral therapy (ARVT), the use of exams that show the immunological defense and resistance levels (CD4/8), and the quantification of the virus in the blood stream (viral load). These advances, indispensable for the prevention and monitoring of opportunistic infections, as well as for other health problems, have contributed to adherence to treatment, reduction of morbimortality rates, and a decrease in the number of hospital admissions, while promoting a better quality of life for PLWHA.

Despite advances in HIV/AIDS therapies, challenges related to the development of psychological problems and mental disorders remain. According to research findings presented at recent international conferences (Navia, 2011; Ragin, 2011), there is evidence that ARV drugs are not able to prevent HIV from entering and affecting the neural tissues of the brain. These neural tissues end up functioning as viral reservoirs with minor to major consequences for the mental health of PLWHA, who may present symptoms such as memory and cognitive difficulties, and anxiety and distress, among others (Christo, 2010). Some of these consequences remain difficult to measure and more studies are needed in this area. Such effects may be more evident in people who begin treatment during later stages of the disease because high viral loads can amplify the action of HIV in brain cells.

Some opportunistic infections (OI), e.g., neurotoxoplasmosis, may also cause damage that compromises the mental health of PLWHA. Because the brain is acutely affected by this infection, neurologic pathologies may result, as well as symptoms of depression, aggressivity and sadness, among others. In this sense, it is important to chart the history of OIs of PLWHA, in order to evaluate whether psychological symptoms may be related to social or to clinical factors, or even whether they result from the interaction between the two. Co-infections, for example, among those who not only have HIV but also develop tuberculosis (TB), or TB carriers who develop AIDS, must also be taken into consideration, because both illnesses are stigmatized, and one may exacerbate the other, with consequent emotional and psychological problems. These psychological problems and mental disorders may be caused by the HIV infection itself or may be aggravated by it. Therefore, it is essential to chart the histories of PLWHA in order to determine whether or not HIV is causing or aggravating problems.

1.3 Socio-Cultural Dimensions of HIV/AIDS

The so-called "AIDS social epidemic," interpreted by various authors as an epidemic of fear, panic and prejudice, continues to be a serious epidemic, in spite of past and current governmental and social/community organization initiatives in fighting stigma, prejudice and discrimination associated with HIV and AIDS. This aspect of the epidemic appears to be a major factor in in the formation of people's attitudes, social representations, perceptions and reactions to HIV/AIDS, all of which have a negative impact on the mental health of PLWHA, their friends and families. This may lead to what is known as "social death" which occurs when such individuals end up being excluded from social interactions and interpersonal relationships.

> "In order to fight social death, the sick person needs to break down the barriers of clandestinity. I believe that we all have to cure ourselves of shame, guilt and fear. That is why it is necessary for people with AIDS not to hide themselves. They need to show themselves as they are, talk about their condition, and build self-help groups and social participation." (Daniel, 1994, p. 11)

There are still many cases of PLWHA experiencing rejection, isolation, loneliness, and symbolic and physical violence, which occurs from the moment they receive a positive diagnosis, regardless of social class or status, level of education, profession, age group or lifestyle.

When someone is faced with a positive HIV test result, questions and complaints may arise, such as: "Why is this happening to me?" "Why me?" "What did I do wrong?" "With whom and how should I discuss this result?" "From whom and where should I seek help?" "What will I do with my life now?" "Is it worth to keep on living?"

An HIV+ result and beginning ARV therapy usually require significant changes in people's lives and routines. When taking these repercussions into consideration, it is important to include and discuss, during post-test counseling and follow-up, aspects such as: information about HIV and AIDS, treatment, the importance of self-care and the strengthening of self-esteem, reaffirmation of goals, changes in habits and behaviors, identification of referral contacts, sharing, living with others, and social participation and inclusion.

Psycho-social follow-up and psychotherapeutic care should take into consideration the needs and characteristics of each individual and his/her lifestyle, type of work and sexual orientation.

Healthcare approaches and strategies cannot be the same for men, women, children, adolescents, transvestites, sex workers, gay people, the elderly, serodiscordant couples, or users of alcohol, crack or other drugs. The specificities, peculiarities and uniqueness of each person must be taken into account. It is necessary to highlight the importance of prevention inputs (male and female condoms, lubricant gels, harm reduction kits) as effective prevention measures for controlling HIV transmission and opportunistic infections, while also emphasizing the need for the consistent use of these inputs. Other aspects, too, must be kept in mind: experiencing one's sexuality, the dynamics of and agreements in relationships, desire to have children, fear of rejection, and debunking the myths about reduced pleasure.

Various clinical issues also have a direct impact on social, cultural and emotional aspects of the lives of PLWHA. One of these relates to lipodystrophy, a syndrome that causes physical and metabolic changes that are viewed as adverse events or collateral effects associated with the use of ARV drugs. Being sexual while having a body that has undergone drastic changes beyond societal norms is a great challenge for PLWHA (Terto, Jr., 2006). The loss of peripheral fat in regions of the face, buttocks, legs and arms, as well as the accumulation of fat in the mammary, abdominal, dorso-cervical and submental (neck) regions may have a strong impact on an individual's sexuality, self-esteem and social relationships, as well as in the workplace.

These physical changes also end up reinforcing stigmas and hindering adherence to treatment regimes, leading patients to avoid beginning therapy or to abandon it as a result of their fear of possible physical changes. Seropositive transvestites, for example, are among the populations that are most afraid of these adverse events. The repercussion of physical changes on mental health may aggravate already existing anxieties and distress such as those related to the social exclusion that many transvestites face.

In general, the physical changes that result from lipodystrophy affect men and women primarily in how they see themselves as "men" or "women." The loss of muscle mass in legs and arms, for example, and the accumulation of fat in the abdominal area – in addition to the effects of the disease in those who have developed symptoms – may make men feel less masculine or incapable of presenting themselves as potential sexual partners. The same may happen to women: they may feel less feminine due to a loss of their former shape because of physical changes in the appearance of their waists, thighs and buttocks. This can also influence their ability to project themselves as potential sexual partners. The impact of these changes on their self-image makes it difficult for them to attract sexual partners and may result in considerable consequences for their mental health. Many PLWHA in these conditions may return to isolation and clandestinity and give up on leisure and pleasurable activities such as going to the beach or out dancing because of feeling too embarrassed to exposing their bodies in public.

According to Grimberg (2003), the mobilization of internal and external resources for managing life with HIV/AIDS is a dimension that cannot be ignored. Mobilization of internal resources relates to the use of previous experiences in dealing with extreme conditions or diseases, keeping secrets, or redefining social and sexual identities in order to deal with the new situations imposed by HIV. Some HIV+ men draw on previous experiences (such as those related to the moment they had to reveal their homosexual identity, i.e., coming out) in order to find the strength to deal with the possible assumption of a political identity as an HIV+ individual, to handle issues such as the revelation of the HIV diagnosis, and to fight clandestinity, among others (Carricaburu & Pierret, 1992).

1.4 Vulnerabilities and mental health

During the historical process of the construction of concepts and social representations of vulnerabilities, diseases and falling ill, the notions of the risk (real or imaginary) of transmission, morbimortality and incurability, as well as the associated myths and metaphors, may trigger psychological problems and mental disorders.

In societies where individual abilities and potential capacity for material production are essential requirements for social inclusion and recognition of a place in society, the situation of a chronic, infectious and contagious disease is intimately associated with notions of lack of ability, disability, physical and emotional dependence, social uselessness, financial costs (social security systems: health, assistance and pension plans), and social and economic costs for public policies, which are core issues for the neoliberal project within the so-called Social Issue (Castel, 2007).

In the social exclusion process faced today by the more vulnerable segments of the population, PLWHA, those affected by HIV/AIDS, and individuals presenting psychological problems and mental disorders are affected socially and economically due to their personal limitations and incapacities, which may be temporary or chronic and may result from their physical and mental health conditions. These segments of the population appear to have greater difficulty in entering the labor market, in accessing education and healthcare and in participating socially and in the community. Again, the reactions and manifestations related to stigma, prejudice, discrimination and violations of human rights constitute etiological factors of psychological problems, mental disorders, HIV infections and reinfections, and, consequently, situations of social exclusion.

In order to understand and deal with these various dimensions, they need to be seen in a new light and require the building up of interdisciplinary knowledge and strategies to implement an effective network that focuses on integral healthcare for PLWHA. Political, technical and operational responses are needed, a process that involves all sectors responsible for the development of public policies. But it is also fundamental that the subject/user become co-responsible for his or her own health. The repercussion of an HIV diagnosis develops in various ways and starts with the life story of the individual and the ways in which he or she has dealt with vicissitudes in the past. By listening carefully to how individuals have reacted in the past, healthcare professionals may collect information useful for guiding their practice and evaluating individual, social and programmatic vulnerabilities.

A person's vulnerability to illnesses or to HIV infection results from a set of characteristics of sociocultural, economic and political contexts that may increase or lower an individual's risk (Ayres, 2002). This risk is used as a tool to quantify the probability of people or populations becoming ill by identifying the cause–effect relationships between the occurrence of diseases and other circumstances and events. In this way, vulnerability and risk are interconnected concepts, as in the case of an individual under the influence of alcohol and other drugs or of someone suffering a psychological crisis who does not take into account the importance of using condoms during sexual intercourse. Such situations of vulnerability expose the individual to a greater risk of HIV infection.

The reflections below consider aspects of mental health from the point of view of vulnerabilities, a concept that has been incorporated throughout the history of the process of fighting the AIDS epidemic.

An individual's vulnerability is associated with behaviors that create opportunities for a person to become infected and/or get sick – risk factors for HIV transmission are well known, i.e., unprotected sex, excessive use of alcohol and other drugs, exposure to contaminated blood, and vertical transmission. A person's vulnerability depends, therefore, on the amount and quality of information that individual has on this problem, his/her ability to absorb this information and how he/she incorporates it into his/her daily practices and effectively transforms his/her behavior. The adverse effects of drugs used to treat HIV infections – among them the bodily changes caused by lipodystrophy and the damage caused by opportunistic infections – have repercussions on people's mental health.

From a sociocultural point of view, the stigma of AIDS may be reinforced by other stigmas related to gender, race, sexual orientation, economic status and use of drugs, among others (Parker & Aggleton, 2003). In particular, there is a need to consider the interaction of stigmas related to AIDS and to mental health, principally in those who have already had a history of mental disorders prior to HIV infection. Understanding how these different stigmas interact may be a fundamental component of a program to promote mental health among PLWHA.

Social vulnerability is also related to a combination of social, political and cultural aspects such as access to information, level of education, power to influence political decisions, ways to fight cultural barriers, etc. Therefore, it may be understood as a mirror of social welfare conditions that involve access to housing and to consumer goods, and degrees of freedom of thought and speech: the lower the control over the decision-making process, the greater the vulnerability.

In order to evaluate the degree of social vulnerability, it is necessary to know the daily living conditions of social groups, such as, for example, the current condition of women in society (lower salaries, lack of protection laws, exposure to violence and restrictions on exercising civil rights), which may increase their social vulnerability to the epidemic.

From a programmatic point of view, the quality and availability of access to healthcare must be taken into account. The guarantee of universal access to HIV/AIDS treatment and to prevention inputs presupposes the existence of organized and welcoming services. Environments with a high level of homophobia and prejudice against gender, race and class, expressed in physical or verbal violence may lead to psychological problems that result in stress, recurring fatalistic feelings and behaviors, and encouragement of clandestinity. A lack of resources and a hostile social environment that deny HIV+ individuals (or any citizen) the realization of their pursuit of happiness are decisive factors that aggravate physical and mental health problems.

At the institutional level, vulnerability requires that policies and actions organized by the government, private sector and civil society be well-defined in order to reduce the rates of the disease. The greater the commitment to integration and monitoring of prevention and healthcare campaigns, the greater the probability of strengthening individuals and society.

When promoting the mental health of PLWHA and of individuals presenting mental disorders and psychological problems, many aspects must be taken into consideration: the conditions of vulnerability in the various social, demographic and socio-economic situations; the age group, race, gender identity and sexual orientation; whether the patients are children, adolescents, adults or the elderly; the different levels of education; cultures; and different degrees of access to basic social services, education, healthcare and work. The following chapters address aspects related to the promotion of mental health not only for healthcare users but also for healthcare professionals, with the purpose of improving the quality of life of all concerned.

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Chapter 2

The subjective dimension of healthcare in HIV/AIDS services

Illustration: GAG

After a in-depth analysis of the dimensions of living with HIV/AIDS, it is necessary that we, as healthcare professionals and according to the specific characteristics of each field, take ownership of the intervention possibilities in this field, keeping in mind the inherent subjectivities and possibilities for maximizing actions, based on the guiding principles of the National Healthcare System (SUS) and other concepts developed in the area of public health. A fundamental understanding of the notions of interdisciplinarity, integrality, healthcare and national policies for humanization of services may facilitate the incorporation of the emotional aspects present in the life of people who live with or are affected by HIV/AIDS.

This chapter discusses the founding principles of integral healthcare practice, which are included in SUS's principles and are being improved through the development of new concepts and policies. Understanding mental health beyond psychological suffering means understanding the psychological aspects of life that may, at some point in life, directly or indirectly interfere in health and sickness processes as well as in treatment. Therefore, including this aspect of life in integral care means maximizing the results of interventions and represents, for healthcare professionals, the full exercise of extended clinical practice.

2.1 Interdisciplinarity at SUS

Provision of healthcare services involves diverse fields, each having its own knowledge base relative to the type of assistance it offers, as well as its own limits. This results in a multifaceted environment where each area of expertise is responsible for one specific type of care but is not always able to produce an effective response to the needs demanded by users (Benevides & Passos, 2005). It is necessary to recognize that no specialty on its own is able to care for all of a person's healthcare needs.

Interdisciplinarity of healthcare means no longer looking at care from the point of view of each specialty as it relates to the individual or the practices within each specialty in the production of knowledge; interdisciplinarity means following the various themes in patients' lives, and making possible, via horizontal communication between the various scientific fields, the creation of new ways of practicing healthcare.

Changing the way healthcare professionals work has become a demonstrable way in which to undo the dissociation between the predominant discourse and routine practices. It has strengthened the observation of phenomena as a source of knowledge that is superior to antiquated doctrines which do not value the principles of integrality of providers and users of the healthcare system. Work, from the point of view of integral healthcare, requires its collective construction by teams that deal with daily issues and learn from their own experiences, building up knowledge and practices based on reality (Gomes, Pontes & Rocha, 2007, p. 23).

2.2 Integral healthcare

Integral healthcare is one of SUS's core principles and is described in current law as the "coordinated and continuous set of preventive and curative actions and services, individual and collective, required for each case, at all levels of the complexity of the system" (Law No. 8080). Its importance is related to the fact that it is this principle that ensures the offering of the most complete follow-up possible, regardless of the level of complexity required by the user's problem, and promotes a systemic view which results in a biologic–psychologic–social understanding of the individual.

When work focuses on guaranteeing integral healthcare, all needs of the individual in question should be taken into consideration, and professionals must improve their listening skills and the assistance provided, as well as options for referring the user to the appropriate service network.

It is important to be attentive to the existence of a hegemonic paradigm for healthcare practices in accordance with the structures and norms of the "ideal universe" to which each case may be compared. According to Gramsci (2001), a discourse is defined as hegemonic when it is shared by a group that has similar ways of thinking and acting, using as a framework a given concept of the world that, because it is so prevalent becomes "common sense." This framework encompasses the health and sickness process based on differentiating between what is normal and what is pathological, concentrating health and sickness practices on the "sick" part of the individual, in an isolated manner. The result is standardization. However, there is no single way to promote health; the principle of integral healthcare points to the need to understand individuals in all their dimensions, without isolating or focusing only on the sick part.

An example of this is the absolute standardization of the use of condoms by all people as a prevention measure, without taking into consideration the specific characteristics of the various segments of the target population. A woman who has been married for 30 years and who has never used a condom in a sexual relationship needs to be approached and accessed with a certain type of language that is different from that which would be used when talking to a young woman just beginning her active sexual life. It is necessary to take into consideration the dynamics of the relationship and the skills needed to negotiate the use of condoms with partners. There are also more subjective aspects, such as the desire to bear children, which may interfere with the prevention strategy. In spite of these contextual differences, when integral healthcare is not taken into account, both the older woman and the younger one may receive the identical standardized guidance during counseling sessions.

With this in mind, one should be aware that providing integral healthcare presupposes the orchestration of working in a team, resulting in a composition of strengths, knowledge and practices, harmonization of professional practices, affirmation of differences, and acknowledgment of the wisdom of other team members in order to achieve the desired outcome (Bonaldi, Gomes, Louzada & Pinheiro, 2007). Comprehending the importance of each member is fundamental to the work, increases feelings of belonging to the team, and results in greater commitment, over and above specific knowledge or a predetermined form of working (Bonaldi et al.).

However, the issue of integral healthcare must be given priority over the reorganization of practices and care offered by the team. The biomedical view is often imposed, and it is not uncommon to see the goal of controlling the disease conflict with users' personal objectives. When there are issues related to the user's desire to bear children, the seropositivity of a partner, adhesion to treatment, or disagreements over revealing the diagnosis of children and adolescents, the team often prioritizes its own goals at the expense of the desires of the user.

It is important to discuss the centralization of measures for controlling the disease, because this centralization may lead to viewing interpersonal aspects as mere tools for behavioral changes in the direction established for the control of the disease (Ayres, 2009). What happens to users' autonomy when their decisions are contrary to what is prescribed by the provider? What should be done when users resist taking medication? Or what should be done when the female user does not want to incorporate the constant use of condoms in her sexual relationship with her HIV-positive partner? Is non-adhesion the team's failure? If so, do assistance, counseling and groups exist for standardizing users' behaviors? How does one accept the other? How does one deal with the other?

Managing healthcare relationships should not be used to move individuals in the direction determined by scientific knowledge. Healthcare technologies should be based on the acknowledgement that there is a broad and diverse set of professional interventions, involving relationships that must be sustained regularly, with the purpose of transforming one or more of their existential, objective or subjective dimensions (Oliveira, 2009). Therefore, managing relationships with the purpose of producing bonds and interventions must be firmly anchored in ethics. The technologies of relationships must be used in the service of the exercise of citizenship, of increased autonomy, of greater co-accountability and of the reconstruction of life goals, never as a mere tool for therapeutic success that ignores users' desires and history. Integral healthcare is more than assistance, treatment and control of the disease – the meeting between provider and user is the space for care.

2.3 Healthcare

Healthcare is characterized by listening to what the other desires, by incorporating a subjective dimension, and by the inter-subjective meeting in which the parties seek mutual understanding and empathy so that care is not limited only to technology, standardization, consensus and instrumental intervention (Ayres, França, Jr., Calazans & Salletti, 2009). The future of the relationship between integral healthcare and care, with the democratization of relationships and team work, will result in the construction of spaces for reflection and the negotiation of new objectives and means to be used in health practices (Peduzzi, 2009). It will result in an inter-subjective agreement based on results related to health needs and to users' and populations' ways of life.

In the case, mentioned above, of the woman who has been married for 30 years, the provider needs to have an understanding of what would it be like for her to discuss the use of condoms in her marriage, how her partner might respond, and how she would react to his response; the provider needs to examine the entire situation in order to find possible paths for this user, and to enable the joint construction of a desired and comfortable path for facing the challenge of self-protection. The healthcare professional must respect the user's right to make decisions and that the user knows what he or she needs.

Establishing new institutional organizations and devices for redefining and reorganizing healthcare processes is a requirement for changing models of healthcare delivery. For this reason, the Ministry of Health created a tool called the National Humanization Policy (*Política Nacional de Humanização*: PNH) (Brazil, 2003).

2.4 The National Humanization Policy

Humanization is a concept that integrates the good use of technology (equipment, procedures and knowledge) with the existential projects of users. For example: What is the use of an increase in the life expectancy of a target population if this additional time is accompanied by the social death of the individual? Reversing or minimizing harm only makes good sense if it comes with gains or achievement of conditions that are valued by the person assisted. Healthcare services need to take into account human projects and participate in their construction (Ayres, 2006).

The NHP has arisen as an effective proposal for integrality in healthcare, as a means for improving interactions among team members and as a way to prepare them to handle the subjective dimension of healthcare. But it also encourages the horizontality of relationships and can be used as a device for fostering co-management and the valorization and inclusion of managers, providers and users in the health promotion process. The NHP attempts to convince healthcare providers to participate in the discussion and formulation of public health policies, in contrast to a healthcare model centered on a complaint–action relationship. It deals with the construction and activation of ethical, aesthetic and political attitudes, in symphony with a project of co-responsibility and strengthening of bonds among healthcare professionals and between them and users in the promotion of health. It is a permanent network for the construction of citizenship, which implies change in the culture of healthcare delivery to users and in the management of work processes (Brazil, 2003).

The most important principles underlying NHP are transversality and non-dissociability between healthcare delivery and management. In order to achieve transversality, it is necessary to increase the degree of intra- and inter-group communication and to destabilize the frontiers of knowledge, territories of power and behaviors instituted in the constitution of work relationships (Brazil, 2003).

2.4.1 What is required for the implementation of NHP in STDs/AIDS services?

- *Rethink the centrality of clinical control of the disease in providing healthcare in order to take into account patient autonomy and to question the standardization of behaviors based on team expectations.* For example: it is common for mothers to bind their breasts or take medication in order to inhibit lactation, but how should the distress of the patient who is prevented from breastfeeding be dealt with? Taking these feelings, emotions and desires into consideration does not necessarily mean that breastfeeding should be permitted, but it does open up a space for reflection and for providing information, and is conducive to giving her an active role in the healthcare process.

- *Promote the inclusion of users in the solutions of their problems.* It is common for decisions and responsibilities for treatment to be limited to professionals. Usually, users have a say only in minor things, such as adjustments in mealtimes and frequency of appointments, as long as they correspond to the expectations of the specialists. The commitment to change will be more effective if, instead of making a commitment with the specialist, the user makes an agreement with him- or herself, mediated by the specialist.

- *A user needs to be seen as autonomous and not as an object of intervention. Healthcare teams need to listen to the desires of users, even when users' priorities do not coincide with the team's*. When users articulate their questions, fears, and desires, these then become elements for dialog, which is a way to overcome the unilateral and monolithic model that may result from a focus on the "means to an end." Users will only open up if they believe that they will be accepted. Consider, for example, the case of a user who has interrupted medication: if the relationship developed by the healthcare system with this individual is based on scolding and an insistence on results, the most likely outcome is that this patient will avoid going to appointments or may lie to the professional. If, on the other hand, the healthcare professional develops a relationship with the user based on mutual respect and partnership, that user will be more likely to seek healthcare services and to talk about the desires and the motivations that led to the interruption in treatment, opening a window for joint reflection that can help the user make informed decisions, even if they differ from those chosen by the professional.

- *Reinforce the concept of the "extended" clinic: this means commitment to the individual and his community, encouraging various therapeutic practices and promoting co-responsibility among managers, workers and users in the process of health promotion.* Examples: gaining an understanding of the history and context of users beyond the physical complaint; assigning a point-of-contact professional for each user; building individual therapeutic projects with the participation of both the user and the healthcare team.

- *Sensitize healthcare teams to domestic violence (directed at children, women and the elderly) and to the issues of prejudice (sexual, racial, religious and others) and discrimination when admitting and referring patients, so that users are empowered to confront these assaults.* In order to do this, inter-sectorial discussions are essential. Examples: mapping governmental and non-governmental resources available in the community for establishing partnerships and examples of referral and counter-referral[2]; broaden the debate around stigma and discrimination related to HIV/AIDS infection and create strategies for combatting these problems.

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[2] Referral is when a primary care doctor refers a patient for secondary or tertiary care; counter-referral is when a secondary or tertiary care doctor refers the patient to primary, secondary or tertiary care.

- *Adapt services to the local and cultural environment, respecting privacy and promoting a welcoming and comfortable space.* Examples: adopt use of the social name of transvestites and transsexual people during the provision of services (norm contained in Ordinance No. 1820 (published on August 13, 2009), which provides for the rights and obligations of health users); provide access to services and ensure the availability of healthcare services to users during times of day when patients can to commute; offer evening hours a few days per week for patients who cannot come to appointments during regular daytime hours.
- *Provide the necessary means for the participation of healthcare workers at clinics (through management committees) and in Local Health Councils.* Examples: promote workshops on societal control for workers and users; in places of high visibility, publish the days and times of the Municipal Health Council meetings, as well as their resolutions; and encourage the participation of users and workers in societal control.
- *Institute admitting/reception policies and procedures within the services.* Admitting/reception is not a space or a locale, but an ethical posture: it does not mean a specific time or professional who provides it, but rather implies sharing knowledge, anxieties and novel ideas, assuming the responsibility to "give shelter and warmth" to meet the other's demands, with the responsibilities and problem-solving capabilities related to the situation at hand. It presupposes that, during the provision of services, listening will be prioritized whenever the user needs it, without the need to make appointments and without barriers to the meeting. Example: if an HIV-positive person suffers discrimination and seeks out the service in order to express their feelings, he or she should be able to find a professional available to receive him/her, regardless of whether or not any physical symptoms are presenting during that specific moment.
- *How subjectivity manifests itself and understanding how this relates to the promotion of mental health should be taken into consideration while incorporating a conceptualization of prevention that goes beyond the prescription of individualized solutions or just blaming the user.* This view of health promotion emphasizes a continuous process for the development of psychosocial skills which will permit individuals to grow socially and affectively, in a balanced and autonomous way, and not as an accumulated set of information and norms. Example: when a healthcare professional impedes a user from expressing her desire to bear a child, isn't the professional impeding this desire? Or, when the healthcare provider rebukes a woman who got pregnant, is not this provider undermining the trust between the user and provider? Will this woman now feel comfortable enough to talk about the possible distress and feelings of guilt that will come with the pregnancy because of her fear that the child may become infected? These anxieties and self-imposed silences may cause immunological imbalances in the user or other symptoms such as hypertension, headaches or sleep disorders. Ignoring these issues may lead to the use of medications in situations that could have been solved through appropriate reception and listening in a safe and trusting environment that favors the therapeutic bond and promotes health.
- *Implement an information and communication system that promotes self-development and broadens the social commitment of healthcare professionals in a democratic manner and without reiterating the asymmetries between users and professionals.* Example: A constantly updated bulletin board facilitates the exchange of information in healthcare facilities.
- *Promote actions to stimulate and value team work and participation in continuous education processes that give credibility to team practices and their inclusion in the Healthcare Network*. Many services specialized in HIV/AIDS find it difficult to promote intra- and inter-sectorial contact with other institutions (e.g., family health teams, basic health units, outpatient facilities, small and large hospitals, specialized centers, policlinics, churches, schools, community associations, NGOs, Health and Guardianship Councils and police stations, among others) or to understand their own place in the logic of the service hierarchy. It is important to open up possibilities for the implementation of a team's continuous education, in particular, to include discussions on how to structure individual and collective work processes by jointly portraying the strengths and weaknesses of the team for offering care, and how to build educational processes at work and in support of the work, while covering topics that are meaningful for all the workers in the healthcare unit involved.

2.5 Why Discuss Mental Health in Services Specialized in HIV/AIDS?

The term “mental health” has generally had a negative connotation. Mental health is not the presence or absence of psychological problems. **Mental health presupposes the appropriate management of life’s events, including the handling of psychological problems in such a way as to keep them from impinging on the quality and continuity of our daily lives or the maintenance of social and affective relationships.**

Psychological pain does not necessarily result from a mental disorder. For example: there is the suffering the individual experiences when he or she receives the diagnosis which is part of processing information about his or her serological status, and is common to most patients, although for some, it is a source of anxiety and mental distress. Identifying similar situations and being receptive are actions related to mental health that should be the responsibility of all healthcare workers. Providing counseling and referring the user to specialized care is an action that requires the help of a professional.

- **Whose responsibility is it to provide assistance when there are emotional issues?**

The association between mental health and the absence or presence of mental disorders may cause the team to try to avoid identifying a set of situations that are intimately related to how the patient expresses what is happening and what is causing psychological pain. These situations do not always require specific expertise in order for them to be identifies and managed. However, in general, healthcare professionals tend to think that they need specialized training in order to be able to attend to a psychological complaint.

It is true that some situations require specialized technical handling; however, in order to identify these situations, the provider needs to listen to the patient. Example: the user sees his or her body undergoing physical changes during treatment, experiences the collateral effects of medication, spends an entire month storing up questions, but upon arriving for the appointment, finds that only clinical exams and adhesion to treatment are discussed, and the other issues of concern to the patient – physical changes, side effects, etc. – are ignored. This reaffirms the fact that only the disease is being seen and not the patient. Healthcare professionals need to become users’ partners and feel co-responsible for their health. Therefore, embracing affective and subjective issues is one of the responsibilities of all healthcare professionals.

- **What are the subjective or psychological factors?**

The subjective dimension is present in all healthcare situations and includes how users see the presence of HIV/AIDS in their lives, the feelings that emerge from this experience, the context of their lives, and the social situations that result from the presence of the disease, such as the need to use medication in the workplace, communication with partners, changes in diets and routines, social support, etc. Often the subjective dimension is the cause of mental distress and determines how people act and react to situations. The psychological aspects of the problem are “the manifestation of human subjectivity when faced with the disease, such as feelings, desires, verbal expressions, thoughts and behaviors, fantasies and memories, beliefs, dreams, conflicts, as well as the lifestyle of the well and the lifestyle of the sick” (Simonetti, 2004, p. 16).

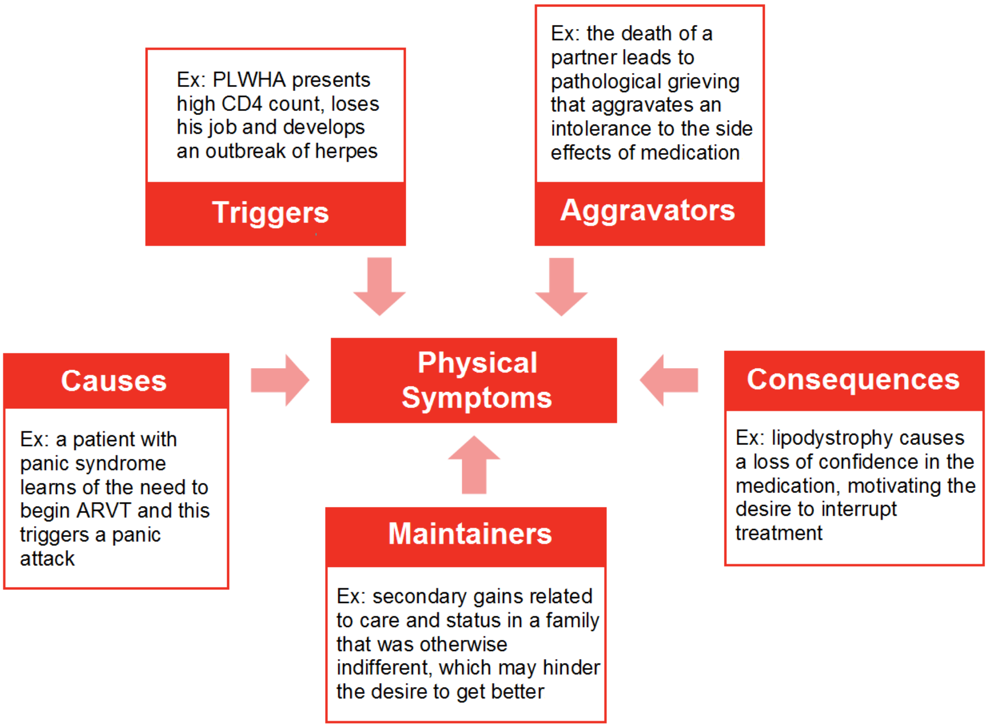
- **Psychological factors can be the causes, triggers, consequences, aggravators, or maintainers of physical symptoms.**

1. When psychological factors are the **cause** of a physical symptom, the user already has a diagnosed mental disorder and this condition is the cause of the symptoms presented.
2. When psychological factors act to **trigger** physical symptoms, these symptoms are the result of another illness that is exacerbated by an emotional condition.
3. When psychological factors are a **consequence** of physical symptoms, they result from the difficulties in handling situations that arise from the main problem.
4. When psychological factors are **aggravators** of symptoms, they derive from other situations in the individual’s life which cause the mobilization of his or her emotions and attention to such an extent that it weakens his or her ability to fight the main problem.
5. When psychological factors serve as **maintainers** of the symptoms, the secondary gains of the disease may also be involved in the process. Secondary gains are the advantages and benefits obtained by the patient via symptoms, exams and the condition of being sick in general, interfering consciously or subconsciously in the individual’s desire to get better.

Although for many years the existence of psychological factors was denied, it is not possible to isolate or separate them from human experience. For example, in an STDs/AIDS service, the subjective dimension is present from the moment of the decision to get tested until the results of the test are delivered, in the management of information between family and friends, in living with the virus, in the introduction of medication, in handling the side effects, and in the construction of new social relationships – thus, at all times.

The table below illustrates how subjectivity and psychological factors permeate all aspects of life and how they are always present during times of managing physical symptoms.

The relationship between psychological factors and physical symptoms:



Note: the examples are illustrative and didactic.
Source: Simoneti 2004 (adapted).

An appreciation of complaints that derive from the way in which individuals understand the disease and the world around them and how they perceive themselves and others gives impetus to the practice of strengthening users' mental health.

- **What skills are expected from the healthcare professional who works with people living with HIV/AIDS and/or STDs?**

Counseling, caring and providing assistance need to go beyond the realms of common sense and begin to become part of the practices of healthcare professionals, in a range of possible therapeutic interventions that should be made available to users. Giving voice to subjectivity means helping individuals to reposition themselves in relation to their problems, an aspect that is just as important a strategy as offering extended clinics is, and this concept will be covered in the following chapter.

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Chapter 3

Healthcare strategies for people living with HIV/AIDS (PLWHA)

Illustration: ALB

3.1 Receiving people living with HIV/AIDS

Having previously discussed the complexities of living with HIV/AIDS and its subjective dimensions, this chapter will examine some of the practical possibilities of quality care, starting with the strategies for the reception, active listening and anamnesis, and the inclusion of significant others, family members and/or social networks in the integral healthcare process for PLWHA.

Patient reception is a strategy for providing care that involves the construction of bonds and a trusting relationship among users, professionals and healthcare services. All healthcare professionals who provide services are responsible for making the user welcome. In order to accomplish this, users must be seen as people with rights, and professionals must be ready and willing to listen to their needs, evaluating demands and the possibility of prioritizing care for psychosocial factors related to each individual's uniqueness and his or her life history, taking into account vulnerabilities and avoiding prejudice or judging.

Patient reception

Receiving the user, from the moment of his or her arrival, by the healthcare professional who makes him- or herself integrally responsible for the user, listens to the user's complaints, allows the user to express his or her concerns and anxieties and, at the same time, puts in place adequate scope for ensuring the delivery of care and integration with other healthcare services in order to guarantee the continuity of care, whenever necessary (Brazil, 2004).

The multi-professional team, when receiving patients, should include active and extended listening in order to be able to address the issues raised during the appointment. Thus, care, rather than being unidirectional, becomes a model in which the user is heard and included during the process. The whole team participates in delivering direct assistance to the user. In this manner, the idea of reception permeates all areas of knowledge, as well as all the professional practices of the health center. As a care strategy, a focus on patient reception improves the quality of healthcare services, leading to a more adequate resolution for each case.

In order to exercise this in practice, it is important to maintain a process that keeps team members continually up to date through multidisciplinary coordination, discussion of cases, and the development and validation of protocols. Although the treatment approach is individualized and focused on the user, the existence of protocols that indicate which procedures should be adopted for more common situations facilitates the approach and broadens the capabilities of the professional, favoring the creation of a bond with the user.

The practice of reception, in isolation, does not ensure responses to all of the user's needs. The team must also be in harmony with healthcare networks and social and community assistance services, among others, so that they may adequately refer users in accordance with the diversity of their demands.

We can see a direct relationship between the practice of reception and the concept of the extended clinic, which takes into account the integrality of the subject. And reception should be included as a service strategy in such a clinic. This is defined in the National Humanization Plan (NHP, 2004) as clinical work that considers not only users and their illnesses but also their families and the context in which they live, with the goal of promoting health and increasing the autonomy of users, families and the community. In order to provide this level of care, an integrated multi-professional team is seen as a work tool that allows the construction of bonds with its clients, the elaboration of the therapeutic plan, and the extension of intervention resources for use in the health/sickness process.

Extended clinic

The extended clinic is a clinical practice directed at the individual and the disease, the family and the context, with the purpose of delivering healthcare while increasing the autonomy of individuals, their families and communities. It uses, as a working tool, the integration of the multi-professional team, through the assignment of users to a specific team favoring the construction of bonds, the elaboration of the therapeutic plan in accordance with the vulnerabilities of each case, and the expansion of intervention resources for use in the health/sickness process (National Humanization Plan, 2004).

3.2 The listening dimension in healthcare

The professional who receives the user must value his or her own ability to listen, because it is from this skill that he or she will be able to get to know the person, identify the reason that led that individual to seek healthcare, provide adequate guidance, and build ties, increasing the efficacy of the therapeutic process.

Listening also means showing interest in knowing what is going on beyond what is causing the symptoms of the disease by understanding what may cause suffering; for this, professionals need to make themselves available and open to affect and be affected by the various feelings that may arise in relationships between people (Lancetti, 2008).

For listening to be effective in healthcare, we need to understand the difference between traditional and active listening. In general, the former values registering the symptoms and prioritizing diagnosis and treatment. The latter is based on a new way of seeing which expands the vision of the professional who associates common complaints with users' subjective, social and network relationships, permitting an integral understanding of the patient. To do this, the healthcare professional needs to be available and show sensitivity in order to understand the multiplicity of factors that surround the AIDS phenomenon. He or she should be attentive to issues related to prejudice and stigma, and their repercussions on self-esteem and body image, such as, for example, the consequences of lipodystrophy and other side effects of medication.

To qualify and expand listening, you need to empathize with the feelings that may be expressed in the meeting, attempting to understand what may cause questions or concerns, what is likely to make the user happy or sad, feel safe or insecure, or cause worries or distress, among others. Active listening is seen as a strategy that is part of the actions and routines of all healthcare professionals who conduct receiving and deliver assistance to PLWHA. Paying attention to the listening process is a core component for the construction of bonds and positive relationships with users.

The various forms of communication and expression of the user have to be taken into account. Thus, the professional needs to read between the lines and pay attention to non-verbal communication, such as gestures and movements, manner of respiration, eye contact, tone of voice, and how the person greets you.

Listening also implies that the professional is attentive and open to comprehending his or her own feelings. During moments when the listener allows him- or herself to be affected, intense emotional reactions may result. Feeling vulnerable and reacting to the subjective content expressed by users is natural. The professional needs to evaluate whether the intensity of his or her reactions and feelings generated during a meeting can help or hinder the relationship with the user. The greater the amount of self-knowledge, the greater the self-awareness of the feelings, conflicts, prejudice and limitations that each situation may cause. Evaluating one's reactions to users is an ethical and committed attitude. Chapter 6 will address healthcare provision by and for healthcare professionals.

Based on the above, some facilitating issues concerning the listening process will be presented. In the elaboration of these questions, it is important to:

- Be attentive and sensitive to the uniqueness of each user, to the specific situation being experienced, and to possible conditions of vulnerability.
- Wait as long as necessary and respect the user's moments of silence before asking questions or providing guidance.
- During the meeting, try to ascertain the user's level of knowledge and awareness of the situation.
- Use language that the user will find easy to understand.
- Do not begin the meeting with a questionnaire. Often, posing a single question that shows an interest in the user can pave the way to learning about more subjective issues, and to building a bond and a relationship based on mutual trust.

Below are examples of facilitating questions that may help the professional get to know the user and the context of the user's life.

Questions that show interest and facilitate patient reception:

- What brought you to this healthcare facility?
- Do you know why you were referred here to begin follow-up here?
- Do you have any questions or concerns about your treatment or any previous assistance you have received?

Questions that show that you are open to listening:

- How can I help?
- How do you feel?
- How was your day (week or month)?
- What's your daily routine like?
- How do you feel when you come to an appointment?

Questions about treatment that may help the professional to understand the user's subjective state:

- What does living with HIV/AIDS mean to you?
- How do you feel about beginning and maintaining treatment?
- Do you experience any side effects from the medication? How do you feel about them?
- Do you discuss these things with other people?

The strategy of active listening may open a space for discussing subjective issues related to living with HIV/AIDS and may generate emotional and even lengthy reports, and this may trigger anxiety in the professional who has a need to find a balance in the time he or she has available with the demand for services. However, managing time and organizing the work process in order to focus on active listening is conducive to strengthening bonds, the elaboration of individualized therapeutic plans, and the perception that, through this exchange with the user, opportunities arise for mutual learning and growth which may assign new meanings to psychological problems and healthcare. Thus, it is important for the professional to let the user know that he or she is supportive and shares responsibilities; the professional should also provide information on his or her professional expertise, facilitating possible referrals based on the reception and the process of actively listening to the demands presented. The possibility of accessing the healthcare network in order to refer users based on their needs may reduce the healthcare professional's anxiety levels.

During the appointment, issues may arise about which the professional may not feel qualified to act nor to deliver any type of support or guidance, due to personal circumstances or other reasons. In such cases, it is essential that the professional be given the opportunity to examine and reflect on his or her own feelings, and to share such issues with other team members. Another possible solution is to transfer the case to a team member who feels more qualified to deal with the issues involved and to offer support and guidance to the user. Or, if necessary, the patient may be referred to a mental health specialist. If the healthcare facility does not have a specialist in this area, the user may be referred to a mental health care facility (see Chapter 7).

In conclusion, patient reception and active listening are strategies directed at increasing the quality and horizontality of care, and these also contribute to meeting the needs of the sociocultural and subjective dimensions of the user, as well as strengthening his or her relationship with the institution, thus facilitating the formulation of hypotheses and the delivery of the most adequate assistance for the demands and needs identified.

3.3 Anamnesis

Anamnesis may be used as an initial strategy for obtaining information about the user's life history. It allows professionals to learn about the different aspects of the user's medical history and the evolution of living with HIV/AIDS, as well as the subjective and social aspects involved. Good anamnesis, using language that is accessible and clear to users, facilitates the creation of bonds and a relationship based on mutual trust.

In order to conduct a well-performed anamnesis, the professional must be sensitive to the demands and concerns of the user during the appointment, as well as being open to learning about the disease and to understanding what it means to live with HIV/AIDS. He or she should pay attention to behaviors and non-verbal cues, signs of self-treatment, myths and prejudices related to the disease, and the ability to understand what is being discussed. Based on information provided by the user, the professional can take advantage of the opportunity to answer questions and to give adequate guidance, demystifying the myths surrounding the disease and life with HIV/AIDS.

It is not always possible to conduct a complete anamnesis during a single appointment. The professional should be flexible enough to include the investigation of subjective and social aspects during follow-up appointments, without prioritizing only clinical and laboratory information, such as CD4 and viral load (VL) testing.

Below are a few items that may be included in the anamnesis of an HIV+ individual. We point out that these questions should not be seen as an exclusive and exhaustive list of questions, but rather as a resource to guide professionals.

3.3.1 Living with HIV/AIDS

Receiving the diagnosis is traumatic for most people. Therefore, it is important to investigate how the diagnosis was revealed, and the reaction and feelings experienced due to the manner in which the information was delivered, but it is equally important to know about the user's current feelings with regard to living with HIV/AIDS, and to consider the frequency and intensity of these feelings.

Investigating the fears and myths related to the disease, experiences of prejudice and discrimination, and how the user dealt with the situation is also recommended, such as discovering whether the patient ever wanted to die or ever thought about or planned for his or her own death, or if there were any serious attempts in this direction.

Collecting information about users' current and future plans, what motivates them to get to their appointments, adhere to treatment, go out, work and relate to the world may provide clues about how to handle their needs and how to build a bond with the team. It also may reveal aspects that might interfere with adhesion to treatment.

3.3.2 Medication in the patient's daily routine

An investigation should be made into whether or not the user is undergoing antiretroviral therapy (ARVT). If so, it is important to learn about the subjective meaning of taking the drugs, how the user feels and handles this situation, analyzing if there are associated factors that may hinder adhesion to treatment (difficulties taking the medication, toxicities, use of alcohol or other drugs, keeping the diagnosis secret, and prejudice, among others).

If the patient is not undergoing ARVT, verify his or her expectations with regard to future use of this medication and discuss the myths and fears he associates with this possibility.

3.3.3 Cognitive, neuropsychological and psychiatric factors

In order to provide users with appropriate and improved treatment and a better quality of life, there is the need to consider the possible effects of HIV and/or ARVT. In this sense, it is necessary to identify psychiatric and neuropsychological symptoms (which may be related to cognitive functions).

In order to do this, it is important to find out if there is a family history of mental or neurological disorders or other hereditary diseases; whether there are learning disorders (e.g., whether the user is able to understand the diagnosis after an explanation is given in accessible language); whether there are temporal orientation alterations (e.g., if the user knows the date of the appointment, the day of the week, month, year, etc.) and or spatial orientation disorders (e.g., if the user knows where he is, where he lives, etc.); and whether there are concentration difficulties (interfering with learning, memory and interpersonal relationships).

To evaluate possible memory alterations, the healthcare professional can investigate whether the user forgets important things about his daily routine, such as, for example, if the user knows how much medication he or she needs to take and when to take it or whether the user forgets to take the medications.

Other aspects may also be assessed such as changes in moods and sensory perceptions, or visual or auditory hallucinations. If any of the changes mentioned are observed, the possible side effects of ARVT should be discussed with the team's physician, as well as the need to refer the user for neurological and/or psychiatric evaluation.

Chapter 5 deals with factors related to mental disorders in more detail.

3.3.4 Relationships

Changes in the user affective, social and professional relationships after receiving an HIV-positive test result must be investigated because they help the healthcare professional to identify how the user deals with living with HIV/AIDS.

Often, what keeps people from sharing their diagnosis is their own difficulty in understanding, accepting and articulating their serological status. It is important that the healthcare professional be able to tell the difference between situations of real discrimination and prejudice and those imagined by the user as a result of his or her own prejudices. The latter cannot be ignored because they make it difficult for the user to relate to other people. The healthcare professional can help the user to deal with such situations in a more realistic manner by helping the use face his or her own difficulties and fears.

In this sense, there is the need to find out if there are support networks where the user may share experiences and feelings. If users show feelings of loneliness, sadness and helplessness, a differential diagnosis for depression is necessary, which may require the need for psychiatric and psychotherapeutic assessment and follow-up (see Chapter 5).

Whenever necessary, the healthcare professional can also help the user to reveal his or her serological status to selected persons, or those identified as significant others in the user's social network, in order to demystify fantasies that may arise and to guide all the parties involved using reality-based information.

3.3.5 Sexuality

For most people, an HIV-positive diagnosis will bring with it the need to prevent sexual transmission of the disease. Therefore, it is essential to address aspects related to how sexual relationships are conducted before and after diagnosis.

It is important to investigate the user's relationship with his or her own body, sexual orientation and changes related to sexual experiences after being informed of serological status, such as abstinence, decreased libido or change in the frequency of sexual activity.

Discovering whether or not there is a history of sexual violence associated with HIV transmission is an aspect that needs to be included in the anamnesis in order to underpin guidance and referrals.

With regard to prevention strategies, it is important to investigate any possible difficulties in negotiating the use of condoms and adopting safe sex practices with partners. The healthcare professional needs to identify these difficulties (as well as those related to gender differences), any myths associated with prevention practices (such as the loss of male potency and pleasure, or the use of condoms associated with extra-conjugal relations), and the non-use of condoms due to the desire to bear children. These issues often go unnoticed by healthcare professionals and fail to be investigated.

Another thing that professionals should try to discern is whether or not users are seeking out only HIV+ partners in the belief that it will be easier to reveal their serological status and thus make their sex lives easier. This situation may also be associated with the practice of unprotected sex because users have the false belief that prevention is not necessary between seroconcordant couples. If this situation is identified, counseling needs to be resumed, reinforcing safe sex practices.

3.3.6 Use of alcohol and other drugs

The use of alcohol and other drugs also needs to be investigated with the purpose of identifying the type of drug, quantity and frequency of use; whether the user has undergone or is undergoing some kind of treatment; whether there is any family, affective, or social influence related to the use of psychoactive compounds; whether these drugs are compromising adhesion to treatment; and if there are drug interactions with ARVT. The healthcare professional needs to provide counseling concerning limiting harm from drug use and, whenever possible, assess the user's interest in seeking help, referring him or her for treatment (see Chapter 7). It is important to note that medication should not be interrupted because of alcohol use (Brazil, 2008).

3.3.7 Socioeconomic context

A socioeconomic evaluation of the user with the aid of a professional can help to identify factors that may or may not contribute to treatment adhesion and improving quality of life, among other aspects.

In order to do this, there are certain factors that should be observed, such as: whether or not the user lives alone; if the user has income; whether or not the user works or receives any social security benefits (as an insured individual or beneficiary); what are the user's housing conditions (house, guest-house, shelter, hospice, homeless); the quality of meals; and which benefits the user is entitled to, such as access to FGTS or PIS/PASEP funds, among others.

3.3.8 Religion

In healthcare it is important to understand the religious dimension of the user's life in order to comprehend the person in their entirety, and to understand their values and the way in which they relate to the world.

3.4 Assistance to people living with HIV/AIDS (PLWHA) with a focus on the family

The HIV/AIDS diagnosis impacts and reflects not only on the patient, but also on all the people with whom the individual chooses to share it, such as family members and/or partners. The new reality colors difficult and stirring questions about fear, prejudice, discrimination, what the diagnosis means, transmission, treatment, death, and, is often accompanied by revelations about the person's sexuality. Understanding the meaning and importance of family relationships on the care process facilitates the delivery of integral healthcare to PLWHA.

Whether or not to share the diagnosis is a personal choice and depends on the affective relationship, the level of trust among the people involved and the desire to share such a delicate and personal situation. In general, caregivers or close family members are fundamental factors in establishing a more harmonious relation with the changes that will come.

Understanding the user's family situation is important for adhesion to treatment and delivery of the necessary healthcare services. There are various definitions and possible configurations of a family structure. In order to understand them, one needs to go beyond legal definitions and adopt those categories that take into consideration the subjectivity, complexity and diversity of the affective bonds that make up the daily routine of PLWHA. Below, we present concepts that may help to design intervention strategies based on the delivery of integral healthcare to users and their families.

The Brazilian Constitution (1988, Article 226, paragraph 4) and the Statute of the Child and Adolescent (1990, *Estatuto da Criança e do Adolescente*, Article 25) – both important documents that provide a foundation for the creation of public policies – define a family community as the presence of any parent and their descendants, based on ties of consanguinity. The Social Assistance Organic Law uses the definition of family based on legal and parent–child bonds. These definitions focus on the existence of bonds of legal affiliation, natural or adopted, regardless of the type of family structure in which relationships are inserted (*Conselho Regional*, 2006).

Bonds between family members and/or consanguinity do not always define relationships among family members. Other considerations may be important for decision making by healthcare professionals. For example, in Family System Theory, the concept of family is defined as "… a special type of system with structure, patterns and properties that organize its stability and changes." It is seen as a small human society whose members have emotional ties, direct contact with each other, and a shared history (Minuchin, Colapinta & Minuchin, 1999).

In this sense, a family may be thought of as a group of people united by bonds of consanguinity or convenience, alliance and affinity. These bonds are constituted by representations, practices and relationships that imply mutual obligations. Such duties are organized according to age group and to relationships between the generations and genders that define the status of the person within the system of family relationships. Therefore, it is necessary to go outside the artificial boundaries between family relationships and the individual's significant social network.

A social network is a system composed of people, functions and situations within a context that offers emotional and material support, financial help, the sharing of responsibilities, and various other actions that lead to a feeling of belonging. (Dessen, 2000)

But how can we go beyond family boundaries and reach the individual's significant social network? According to Sluzki (1997), in our clinical practice, we can include various questions that will help identify the boundaries of the network:

- Who are the important people in your life?
- With whom did you talk or meet this past week?
- When you feel like visiting someone, who do you call?
- With whom do you meet on a regular basis?

Aiding PLWHA in delineating their significant social connections can have large effects on both users and healthcare professionals. It allows the concrete identification of people who, if authorized by the user, may be accessed as a therapeutic tool for improving the patient's well-being and his or her adhesion to treatment. Interventions directed at strengthening users' social connections may also reawaken relationships that had become dormant.

There is good evidence that a stable, sensitive, active and reliable social network protects people against disease, acts as an agent of help and referral, affects the pertinence and timeliness of accessing healthcare services, accelerates the healing process and increases life expectancy, i.e., generating better health (Sluzki, 1997, p. 67).

In healthcare institutions, interventions performed together with user's family and social network should be conducted by a multi-professional team. Interdisciplinary actions (such as team meetings, case discussions, extension of services to users and their families and significant social connections, creation of educational and therapeutic groups, as well as visits to their homes, institutions or street dwelling) may contribute to adhesion to treatment and improved healthcare delivery.

In situations where significant ties (family, social network) are absent or precarious, other institutions should be involved. In these cases (and whenever the team deems it necessary), use of intra- and inter-sectorial networks such as Psychosocial Support Centers, Social Assistance Reference Centers, Guardianship Councils (for children at risk), and community organizations should be considered.

3.5 The Brazilian Public Health System and the Brazilian Social Assistance System: Intra- and inter-sectoriality in integral healthcare

3.5.1 The Brazilian Public Health System

The Brazilian Public Health System (SUS) is based on the core principles of universality, integral healthcare and equity, and on the organizational principles of decentralization and societal control of its management, as assigned by constitutional and infra-constitution legislation (Law No. 808, published in September 1990; Decree No. 7508, published in June 2011). Following the concept of the Healthcare Network (*Rede de Atenção à Saúde*: RAS; established by Ordinance No. 4279, published in December 2010), SUS operates cross-horizontally and intra- and inter-sectorally as a network of integrated care and is comprised of primary care units, outpatient facilities, maternity wards and specialized services, as well as Social Assistance Reference Centers, hospices and shelters, among others.

Viewed from this perspective, healthcare services are seen to be organized based on the delivery of primary care which functions as the gatekeeper to and the coordinator of services, offering a range of individual and collective actions related to health promotion, care and disease prevention. Primary care is composed of healthcare centers, family healthcare teams, family healthcare support teams (*Equipes do Núcleo de Apoio à Saúde da Família*: NASF) and Community Health Agent Program Teams (*Equipes de Agentes Comunitários de Saúde*: PACS), all working based on the concept of a pre-defined geographic area and population and the profile of local health conditions, and by mapping institutional partners (schools, healthcare associations, councils). It also focuses on the delivery of healthcare characterized by the high degree of relational technology as, for example, the negotiation of the therapy plan with the user and discussions with the community about collective risks and vulnerabilities.

Specialized healthcare services (*Serviços de Atenção Especializada*: SAE) comprise small, medium and large hospitals, policlinics, testing and counseling centers, psychosocial care centers, hemocenters and oral health centers, among others, with clinics that offer a range of services characterized by a high density of equipment, testing and medicines, as well as a high density of relational technology.

Together, all these elements comprise a continuum with the purpose of offering integral healthcare to users. Interaction among healthcare centers through referral and counter-referral procedures, logistics and norms integrates intra-sectoriality.

3.5.2 The Brazilian Social Assistance System

From the viewpoint of inter-sectoriality, the Brazilian Social Assistance System (*Sistema Único de Assistência Social*: SUAS) is a public policy directed at delivering services to socially vulnerable segments of the population.

SUAS also operates based on the principles of equity, sustainability and individual empowerment, as well as effective public action, and is organized according to the different levels of social protection offered, as described below.

3.5.3 Primary Social Protection

SUAS's main purpose is to prevent the development of risky situations by building capabilities within families and communities and by strengthening bonds. Its work is directed at populations experiencing social vulnerabilities as a result of conditions of poverty, lack of resources (lack of income, precarious or non-existent access to public services, among others), and/or weak affective bonds related to relationships and social belonging (e.g., age, ethnic, gender and disability discrimination). Primary Social Protection is provided by Social Assistance Reference Centers (*Centros de Referência da Assistência Social*: CRAS) via the delivery of continuous services that are seen as "points of entry" to the Social Protection Network.

3.5.4 Special Social Protection

Special Social Protection is a type of assistance directed at: individuals and families experiencing personal and social risk due to abandonment; those suffering from physical, psychological and/or sexual abuse; users of psychoactive chemicals; and people serving social-educational sentences, those living on the streets, and child laborers, among others.

All of these situations require individual follow-up and great flexibility in protective solutions, allowing for monitored referrals, support services and processes that guarantee the desired quality of care and effective social re-insertion. Special protection services maintain a close interface with the systems that guarantee civil rights, often requiring complex, joint management with the Judiciary, Public Ministry and other offices and agencies of the Executive Branch.

3.5.5 Special Social Protection of Medium Complexity

Special Social Protection of Medium Complexity refers to the delivery of assistance to individuals and families whose rights have been violated but whose family bonds have remained intact. It involves greater technical and operational structures and individual and specialized care with systematic and monitored follow-up. It comprises the following institutions:

- Specialized Reference Centers for Social Assistance (CREAS)
- The Sentinel Program: social protection services for children and adolescent victims of violence, abuse and sexual exploitation, as well as their families
- Specific services for the elderly and the disabled
- Child Labor Eradication Program

3.5.6 Special Protection Services of High Complexity

Special Protection Services of High Complexity refer to services that provide assistance to individuals and families in grave situations of violation of their human rights, without family and community ties. These services are for individuals who, due to a range of factors, do not have the protection or care of their families. They include the following institutions:

- Shelters
- Institutions of integral care (nursing homes)
- Guest houses
- Foster families
- Students' houses
- Temporary housing
- Hospices
- Community-based organizations (neighborhood associations, women's associations, cooperatives).

From this perspective, the greater the integration between health and social assistance – made concrete through coordination between professional teams and between teams and communities – the more effective the response to problems experienced by SUS/SUAS's users is. When the healthcare team is able to view families and significant social networks as resources (through reception and active listening), the direction of integral healthcare provided to PLWHA will certainly advance, contributing to the improvement of relationships among all parties.

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Chapter 4

Psychological problems and mental disorders in people living with HIV/AIDS

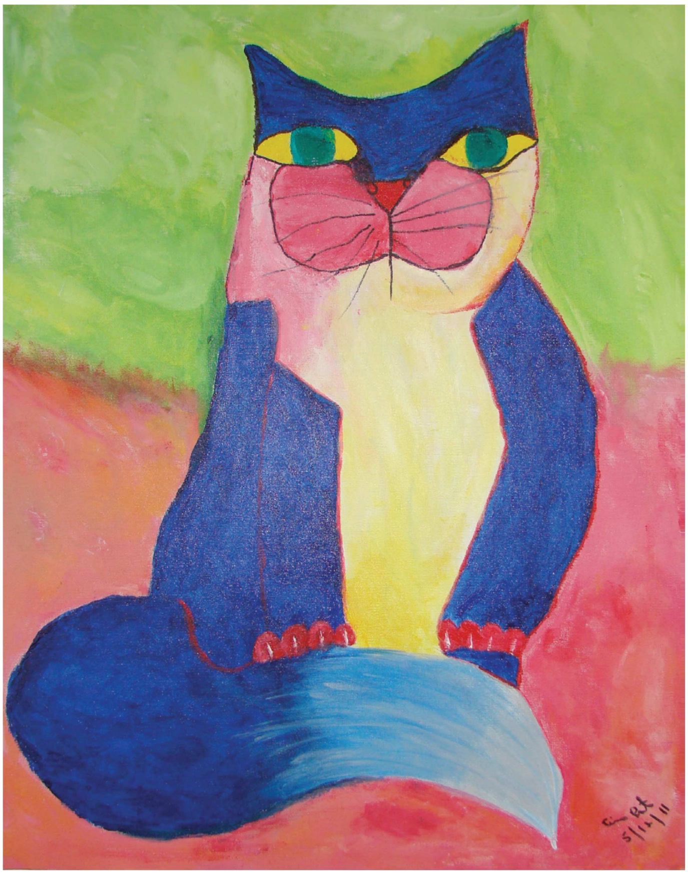

Illustration: CP

This chapter presents analyses of some of the psychological problems and mental disorders that affect PLWHA as well as strategies for addressing and treating these problems.

Psychological factors associated with HIV infection have raised interest among mental healthcare professionals. The infection may interfere with users' mental health due to the direct action of HIV on the central nervous system (CNS), the possible development of neuropsychiatric pathologies and psychological or psychiatric complications aggravated by the diagnosis and its social repercussions.

It is known that psychological problems and mental disorders are more frequent among the HIV-positive than in the general population. Epidemiological studies show that the prevalence of mental disorders among PLWHA may reach 30% (Meade & Sikkema, 2005; Heaphy et al., 2009).

Some of the mental disorders that may occur in PLWHA are related to depression, anxiety, delirium, dementia, schizophrenia, and other psychotic disorders (Brazilian Ministry of Health, 2008a; Campos et al., 2008; Owe-Larsson et al., 2009). The development of these disorders is associated with the revelation of the diagnosis, previous history of mental disorders, and alcohol or other drug use, abuse or addiction. Among the risk factors for the development of psychological problems and mental disorders are: the direct effects of the virus, its opportunistic manifestations that affect the CNS, the chronicity or seriousness of the disease, the side effects of treatment (such as lipodystrophy), social and affective limitations (such as difficulties in maintaining professional activities or sexual relationships) and deciding whether or not to have children (Chander, Himelhoch & Moore, 2006a; Kalichman et al., 2007).

Individuals with mental disorders seem to be at greater risk than the general population at becoming infected with HIV. Patients suffering from schizophrenia (or other psychotic disorders), depression, anxiety, bipolar disorder and abuse of or addiction to alcohol or other drugs seem to be more vulnerable to HIV infection. Other factors, such as having multiple sex partners and engaging in unprotected sex increase the risk of HIV and other STD transmission (Meade & Sikkema, 2005; Campos et al., 2008; Wainberg et al., 2008). A multicentric study conducted in Brazil of 2,475 psychiatric patients showed a 0.8% prevalence of HIV infection in this group, higher than that found in the general population (0.6%) (Guimarães et al., 2009).

4.1 Psychological problems in the context of living with HIV/AIDS

4.1.1 Receipt of the diagnosis

Delivering a diagnosis of HIV infection to a patient is a critical moment in the care of PLWHA. Various factors may influence an individual's reaction upon receiving a positive diagnosis may depend on various factors, such as how this information is communicated to the patient, the patient's history of previous psychopathological changes, their experience in dealing with adverse situations, and the degree of social support (Brazil, 2008b; Galano, 2008).

When informing the patient of the diagnosis, the healthcare professional needs to be gentle and sympathetic and answer any questions a user may have while providing guidance on the best way to proceed with regard to self-care. This method tends to minimize suffering and engage PLWHA in treatment, thus reducing the chances of a psychological shock when the patient is faced with the diagnosis.

However, healthcare professionals also need to be prepared to address reactions of anxiety and distress in patients receiving a positive diagnosis. Feelings of guilt, self-pity, fear and anger may arise. PLWHA may be frightened and afraid of dying, as well as experience difficulties in talking to people close to them about their feelings (Melo & Malbergier, 2006). Decreased self-esteem, limitations imposed by the disease, and being pushed away or abandoned by friends and family members are among factors that may increase the risk of mental disorders developing.

These feelings can be seen in reports when users are asked about their disease (Freitas et al., 2008, p. 91):

> *"AIDS is a disease that leaves a person thin and ugly."*
> *"It's the end of life."*
> *"Whoever gets AIDS is done for."*
> *"What do you think about AIDS? Death."*

4.1.2 Living with HIV

For some, a desire to die may appear very soon after learning of their serological status. In other cases, the development and chronicity of the disease, the side effects of medication, the hopelessness that results from knowing there is no cure, and the unpredictability of the future may trigger a wish to die (Sari et al., 2009).

In situations like these, the healthcare professional may need to deal with patients who are irritable or anxious, cry easily, have excessive complaints and concerns about their physical health, experience decreased social interaction, and have difficulty concentrating on and understanding some of the explanations about their treatment. There may also be frequent complaints about sexual dysfunction and conjugal, professional and academic problems.

These complaints may be associated with factors such as beginning antiretroviral treatment, adverse effects of medication and coinfections that favor the presentation of these symptoms, social and psychological limitations faced by users subsequent to receiving the diagnosis, and the development of a mental disorder (Ciesla & Roberts, 2001; Owe-Larsson et al., 2009).

Identifying and treating these problems are very important. It is known that psychological distress and the development of mental disorders in PLWHA may cause non-adherence to antiretroviral treatment (Sari et al., 2009) and increased risk of HIV transmission (Benton, 2008; Rabkin, 2008; Mosack et al., 2009). Studies show that individuals who suffer from depression, generalized anxiety or panic syndrome are three times as likely to fail to adhere to antiretroviral treatment as those who have other mental disorders (Turner et al., 2001; Chesney et al., 2003). A study conducted in Brazil showed that, among users with low adhesion, 35.8% had been diagnosed with anxiety and 21.8% with depression (Campos, Guimarães & Remien, 2008).

In order to promote users' health and ensure the best approach to each case, it is necessary to differentiate those complaints associated with psychological suffering from those associated with mental disorders. Also, it is important to keep in mind that complaints may be caused by organic problems, coinfections, or the use of certain medications.

4.2 From sadness to depression: approach and management by the healthcare team

Today, depression is considered the most prevalent psychiatric disorder worldwide. According to the American Psychiatric Association (APA, 2004), it is estimated that approximately 5% of the general population have depression. However, the prevalence of this illness may vary from 5% to 47%, depending on the population's characteristics, and the highest prevalence occurs in people suffering from chronic diseases. Among hospitalized patients, prevalence may reach 40% (Maj, 1996; Fleck, 2008). Moreover, opportunistic infections and the use of alcohol or other drugs may increase the risk of an individual developing depression (Ciesia & Roberts, 2001; Mello, Segurado & Malbergier, 2009).

One of the greatest challenges faced by healthcare professionals who assist PLWHA is how to differentiate between clinical depression and sadness caused by living with the disease, the limitations imposed by it, and the difficulties in restructuring one's personal life. This distinction and the work of a multi-professional team helps to develop a more appropriate, efficient and individualized therapeutic plan.

Often, feelings of sorrow and sadness are confused with depression. Sadness is a response to frustration, disappointment, loss or failure, among other reasons for feeling discontent. Through sadness, we show our unhappiness with events in our lives. This feeling tends to be of short duration, and it does not compromise the individual's interpersonal relationships or the ability to perform cognitive functions. Depression, on the other hand, is characterized by a set of symptoms that affect the individual for a longer period of time, decreasing the person's work capacity and adversely affecting relationships with other people (Nardi, 2006).

The table below presents the criteria for the diagnosis of depression, according to the American Psychiatric Association (2004).

Depression is characterized by the presence of 5 or more of the following symptoms:

- Depressed mood during most of the day, nearly every day;
- Loss of interest or pleasure (anhedonia) in most activities, during most of the day, nearly every day;
- Significant weight gain or loss (more than 5% in the last month);
- Sleep disorders (insomnia or hypersomnia);
- Psychomotor agitation or retardation, nearly every day;
- Fatigue or loss of energy, nearly every day;
- Feelings of helplessness or excessive guilt, nearly every day;
- Impaired concentration or indecision on a nearly daily basis.
- Thoughts of death and suicide ideation without a specific plan or suicide attempt.

These symptoms need to cause clinically significant distress or compromise social or occupational functions, be present for at least two weeks, and not be the result of physiological or medication effects.

An **episode of depression** can be classified as **mild, moderate or severe.** The classification varies according to the **number, gravity and duration of symptoms** (APA, 2004).

Individuals with depression normally present a loss of interest and pleasure in activities that were previously viewed as pleasant. This lack of interest may affect complex activities such as work and leisure or those involving meetings with friends and family, as well as simple and vital activities such as, for example, eating something appealing. Changes in appetite are also a component of the symptomatological profile of depression. The individual may complain of a lack of appetite, resulting in significant weight loss, or manifest an insatiable desire to eat, leading to weight gain. According to the American Psychiatric Association's criteria (APA, 2004), to be part of a depressive profile the weight loss or gain must be greater than 5% of body weight.

Fatigue or a feeling of "lack of energy" also permeates symptoms of depression. There is an impression that the effort put forth for conducting any activity is greater than what is actually required for the task. The depressed individual may also present feelings of guilt and lower self-esteem. Healthcare professionals need to recognize negative and pessimistic reactions with regard to the future and feelings of incapability and incompetence in carrying out activities.

Changes in sleep patterns are another sign of depression. Depressed patients frequently complain of insomnia. Insomnia may be related to difficulties in falling asleep as well as in staying asleep. Worries, stress, repetitive thoughts and difficulties in "turning off" the brain with regard to daily activities or difficult situations being experienced by the patient are some of the factors that may contribute to insomnia (Nardi, 2006).

Insomnia may be classified as *sleep-onset insomnia* (difficulty falling asleep), *sleep-maintaining insomnia* **(**waking up several times during the night) or *early- morning awakening* (waking up before the desired time). Individuals with insomnia report sleep-maintaining and early-morning insomnia more often. However, not all patients with depression have insomnia. Sleep disturbances may be described as an excessive desire to sleep or to stay in bed, or spending a good deal of time feeling sleepy (Nardi, 2006). The table below contains suggestions that the healthcare professional may provide to users for improving the quality of their sleep.

Advice for sleeping better

- Keep a regular schedule. Try to get up and go to bed at the same time every day.
- Do not sleep during the day. If you are going to take a nap, do not sleep for more than 15 minutes.
- Avoid large meals, caffeine, nicotine, and alcohol consumption before going to bed.
- Avoid watching TV or loud music.
- Don't watch TV in bed and don't take your laptop to the bedroom. Avoid peaks of concentration before bedtime.
- Go to bed only when you feel sleepy. Do not wait to fall asleep in bed. If you can't fall asleep, get up and do something relaxing.
- If your insomnia is related to some problem or ideas that keep popping back into your head, get up, write down the problem and what you think you can do to solve it the next day.
- Your bedroom should be a place to relax and sleep.
- Sleep in a cozy environment. A comfortable bedroom facilitates sleeping.
- Turn your mattress over regularly, eliminate lumps and squeaks, use comfortable bed sheets and pillow cases, get a nice pillow (that is, one whose height is equal to the distance between the neck and the external part of your arm), use an alarm clock to ensure you do not need to worry about oversleeping, use a curtain that blocks external light, etc.
- Do not go to bed as soon as you get home from work. Take a hot shower, drink some herbal decaffeinated tea and try to relax before going to bed.
- Adopt some routines that you know will help you wind down, such as, for example, relaxation techniques, meditation, breathing exercises, etc. There are CDs with nature sounds (the sounds of wind blowing, rain falling, etc.) which are normally used in meditation environments and which can help you relax.

An individual with depression may also have problems related to the ability to concentrate. Complaints about an inability to maintain focus and to memorize information, indecision about everything, and increased sensitivity to other people's opinions may become frequent.

Below we present two cases that may help to describe the difference between sadness and depression.

> *Beatrice has just received a positive diagnosis for HIV. During the follow-up appointments, the healthcare professional notices that she has been crying easily, has a lot of questions, feels outraged, manifests feelings of guilt, and even thinks she would be better off dead. However, the professional notices that the Beatrice never misses an appointment, arrives on time, shows interest in understanding what she should and should not do in order to feel better. When he analyzes her social, professional and educational life, the professional observes that she has not given up her activities. Over time, the number of complaints and the crying decrease in frequency and are replaced by feelings of hope and a dedication to taking care of her health.*

In the above case, it appears that Beatrice has presented a clear episode of sadness associated with the revelation of the positive diagnosis, but the situation improves over time, and the user does not develop depression. Often, difficulties in solving the problems caused by the diagnosis and the inability to find positive perspectives in relation to the disease may aggravate feelings of sadness, giving rise to the development of depression.

Now, look below at a description of a case of depression whose characteristics are very similar to Beatrice's.

> *John has just received the positive diagnosis for HIV. During subsequent sessions, the healthcare professional notices that John is very sad, cries easily, has lost 18 pounds in the last two months, complains of insomnia, has feelings of guilt and thinks about dying. Along with these symptoms, the professional notices that John has missed some of his appointments. During a meeting with the social worker, the professional discovers that, in the previous month, John quit his job at the company where he had worked for more than 10 years. His partner complains that he is not taking care of himself and that he does not feel like doing anything in or outside the house.*

In John's case, a psychiatric evaluation is necessary due to the intensity and persistence of symptoms. The approach and management of the case need to be conducted by a multi-professional team, while providing a welcoming environment that enables the user to express his feelings concerning his new situation.

It is important to remember that, when diagnosing depression, the healthcare professional needs to verify whether or not the symptoms mentioned above have been caused by organic alterations or by medications. Some antiretroviral drugs (ARV) may affect mood and cause nausea, diarrhea, headaches or neurological alterations, and are associated with the development of symptoms of depression, especially the drugs efavirenz and zidovudine (AZT). The table below lists some of the adverse effects of antiretroviral drugs that may be confused with symptoms of depressions (Oliveira, Costa & Fonseca, 2006).

ANTIRETROVIRAL DRUG	ADVERSE EFFECTS OF ARV DRUGS THAT MAY MIMIC SIGNS AND SYMPTOMS OF DEPRESSION
ABACAVIR	Weight loss*
AMPRENAVIR	
DIDANOSINE	
STAVUDINE	
FOSAMPRENAVIR	
INDINAVIR	
NEVIRAPINE	
TENOFOVIR	
SAQUINAVIR	
EFAVIRENZ	Weight loss* Fatigue Insomnia or drowsiness Impaired concentration Mood changes Sleep disturbances
LAMIVUDINE	Weight loss* Fatigue
RITONAVIR	
ZIDOVUDINE	
ZIDOVUDINE/LAMIVUDINE	

*Weight loss may be due to the following adverse effects: vomiting, diarrhea, lack of appetite.

Some psychoactive drugs may have a depressor effect, such as alcohol, for example. Moreover, substance abuse may be associated with feelings of guilt and resentment. A study conducted by Malbergier and Andrade (2000) showed that 26% of injectable drug users (IDUs) infected with HIV, who were treated for their addiction, had depression, and 43% of them had already had at least one episode of depression in their lives.

Opportunistic diseases may leave the user more vulnerable to sadness and feelings of helplessness. Depression is the most frequent diagnosis in psychiatric referrals for PLWHA (Ciesla & Roberts, 2001).

Depression is also underdiagnosed in PLWHA. The most frequent symptoms (e.g., sadness, discouragement, fatigue, impaired concentration or memory, apathy, anxiety, hypochondria, and diminished libido) are often confused with the adverse effects of medication or with manifestations of the disease itself, hindering differential diagnosis.

Therefore, the evaluation of symptoms of depression must be charted by criteria, while always keeping in mind the stage of HIV disease (AIDS). Structured interviews (e.g., CIDI), specific diagnostic tools such as depression scales (e.g., Hamilton and Beck), and knowledge of the clinical evolution of depression facilitate diagnosis and improve treatment (Hamilton, 1959, 1960; Folstein, Folstein & McHugh, 1975; Cunha, 2001).

In addition to using such tools, professionals need to be attentive to the presence and evolution of symptoms. Factors such as isolation, abandonment by the family and/or partner, and financial difficulties may cause intense psychological distress and, in more serious cases, suicide attempts or ideation (Nardi, 2006). Even more attention must be paid to patients with a prior history of depression or attempted suicide. Professionals also need to give close attention to users who present psychiatric comorbidities such as, for example, personality disorders or schizophrenia, or who have other risk factors such alcohol and drug abuse, because these factors may increase the risk of suicide (Lewden et al., 2005).

It should be kept in mind that depression is a chronic and recurrent disease and that the rate of recurrence of depressive symptoms may reach 80% (Hollon et al., 2005), necessitating the provision of long-term medical and psychological care.

4.2.1 Pharmacological treatment of depression

The pharmacological treatment of depression presents certain particularities in PLWHA. An important factor in this context are the possible interactions between antiretroviral drugs and antidepressants.

More detailed information on pharmaceutical interactions in the field of mental health and HIV/AIDS may be obtained in the *Psychiatric Manual for HIV*, published by the Ministry of Health, as well as in the 2008 *Recommendations for Antiretroviral Therapy in Adults Infected by HIV* (Brazil, 2000, 2002, 2008b).

Pharmacological treatment combined with psychotherapy appears to be more efficient for adhesion, for the response to treatment, and for the reduction and prevention of recurrences of episodes of depression when compared to pharmacological treatment in isolation (Hollon et al., 2005; Fleck, 2008). Psychotherapeutic interventions seek to support users through a process of identifying and managing situations related to disease symptoms and in the development of a repertoire of social skills that increase sources of pleasure and success in daily activities (Martell, Addis & Jacobson, 2001; Abreu, 2006; Powell et al., 2008).

4.3 From anxiety to anxiety disorders

Anxiety is a natural characteristic of being human that anticipates moments of real or imaginary danger. Physical sensations such as an accelerated heart rate, epigastric discomfort, intense fear, chest tightness, and perspiration are some of the symptoms that characterize anxiety.

Symptoms of anxiety are generally associated with situations that involve fear, dread or feeling threatened, or having to make choices or major decisions that affect the future, i.e., situations that place the person in a situation of imminent risk from that person's point of view. In PLWHA, the uncertainties surrounding the progression of the disease and its clinical course and the fears related to pain, suffering, physical changes, treatment and death can generate symptoms of anxiety (Campos et al., 2008).

Let us imagine a case in which the user exhibits symptoms of anxiety but which do not evolve into an anxiety disorder.

> *Joanne, HIV-positive for 5 years, reports during appointments that she feels a bit anxious. The healthcare professional asks her how she feels. Joanne reports feeling insecure and indecisive lately, noticed that her heart has been beating faster, is experiencing emotional discomfort, and is afraid of what will happen in the future. During the conversation, the professional asks her how long she has been feeling this way. She says that her boyfriend proposed about a month ago and*

the symptoms appeared right after that. Joanne says she really wants to marry her boyfriend, who is HIV-negative and is aware of his fiancé's serological status. However, she is really afraid of what might happen, especially in relation to the probability of sexual transmission of HIV. During the appointment, the professional talks to Joanne about her fears and dreams of the future, discussing the pros and cons of her decision, helping her to think about the situation. During the following appointment, the professional asks Joanne how she has been feeling in relation to her symptoms of anxiety and what her decision was with regard to the marriage proposal. Joanne says she has been feeling better, has decided to get married, and is very busy with her wedding preparations.

In Joanne's case, we can see that there has been a real change in her life. The symptoms of anxiety appeared right after she was presented with a major decision to make, and which then disappeared once she had made the decision, and there was no ensuing social or occupational harm as a result.

Let us now imagine a case in which the symptoms of anxiety evolved into an anxiety disorder.

Charles has worked for a company as an IT technician for 10 years. Since he learned about his HIV status four years ago, he has often asked to leave work early in order to go to his medical appointments. At first, his boss and work colleagues did not question his leaving early so frequently. However, although people do not know of his serological status, Charles has noticed that, during the past year, his friends are no longer so close to him and do not invite him out for lunch, and his boss has avoided assigning important tasks to him. This situation is causing great concern to Charles. He feels terrified that his co-workers will find out he is HIV-positive and that he will be fired. He thinks about this all the time. He cannot focus on his job and misses deadlines; clients are complaining about his work. Also, he has insomnia and wakes up with his heart racing and also complains of muscle pains. On Sundays, he wakes up feeling irritated and does not want to go out. He no longer enjoys moments of leisure with his family, and they are complaining a lot about the way Charles has been treating them.

We can see that, in Charles' case, the symptoms have evolved into an anxiety disorder. The symptoms continued for almost a year, damaged his professional life and interfered with his ability to enjoy leisure activities.

When symptoms of anxiety are present in the life of an individual for over six months, causing social and professional harm, they may have become pathological (APA, 2004). Below are the criteria for the diagnosis of anxiety disorder, according to the American Psychiatric Association (2004).

Criteria for the diagnosis of generalized anxiety disorder (APA, 2004, adapted)

1. Anxiety is characterized as excessive worry that is present most of the time, almost every day, for at least six months.
2. The individual experiences significant difficulty in controlling his or her worries.
3. The worry is associated with 3 or more of the following symptoms:
  a. feeling tense or restless;
  b. feeling tired or fatigued;
  c. difficulty in concentrating or a feeling of blankness of mind;
  d. irritability;
  e. muscle tension;
  f. difficulty sleeping.
4. The symptoms cannot be explained better as other types of anxiety disorders, for example, obsessive-compulsive disorder or a social phobia.
5. The anxiety and the symptoms cause clinically significant suffering or compromise the ability to function socially or professionally.
6. The symptoms are not due to physiological problems or drug side effects.

Anxiety disorders include panic, obsessive–compulsive disorder (OCD), specific or social phobias, post-traumatic stress disorder, and generalized anxiety. Generalized anxiety is the most common pathology and affects about 8% of the general population (APA, 2004). The prevalence of anxiety disorders throughout the life of HIV-positive individuals may reach 40% (APA, 2004; Campos, Guimarães & Remien, 2008). The prevalence of other anxiety disorders (such as panic and obsessive-compulsive disorders and social phobia) is lower among the HIV-positive population (Atkinson & Grant, 1994; Johnson et al., 2008).

In PLWHA, some antiretroviral drugs, in particular efavirenz, may trigger symptoms similar to anxiety (agitation, aggressivity and diminished attention).

4.3.2 Pharmacological treatment of anxiety

The pharmacological treatment of anxiety is based on the use of antidepressants and benzodiazepines; however, the administration of psychotropic drugs to PLWHA must be carefully evaluated.

Individual and/or group psychotherapy approaches that focus on handling anxiety and stress, relaxation techniques, breathing and self-massage have demonstrated significant results in treating anxiety and re-establishing a sense of well-being.

4.4 Psychotic disorders

Schizophrenia and other psychotic disorders (schizophreniform disorder, schizoaffective disorder, delusion, a brief psychotic disorder, a shared psychosis, a psychotic event due to a general medical condition, a substance-induced psychotic disorder, or a psychotic disorder without any other specification) are characterized by cognitive alterations, delusion and hallucinations. Delusion is due to imaginary or irrational ideas or beliefs that may be related to feelings of persecution or grandeur, or mania, religious or mystical themes. Hallucinations, on the other hand, are characterized by sensory perceptions that do not exist. Generally, they are associated with the five senses. Users may hear voices (auditory hallucinations), see people or shapes (visual hallucinations), feel something (cold, heat, pain, pressure) over his/her body (tactile hallucinations), or perceive tastes (gustatory hallucinations) or odors (olfactory hallucinations) that do not exist (APA, 2004).

The table below presents the diagnostic criteria for schizophrenia, according to the American Psychiatric Association (2004).

Criteria for the diagnosis of schizophrenia (APA, 2004, adapted)

1. The presence of two or more of the following symptoms:
  a. delusions
  b. hallucinations
  c. disordered speech
  d. disorganized or catatonic behavior
  e. negative symptoms such as emotional numbness

2. Social and/or professional dysfunction for a significant period of time.

3. Continuous signs of disturbance for at least six months. During this period, users must exhibit, for one month, the symptoms described in item 1, which may include prodomic or residual symptoms.

4. Symptoms cannot be explained better by attributing them to schizoaffective disorder or a mood disorder.

5. The disorder is not the result of the physiological effect of the use of substances or of any other general medical condition.

6. There may be a relationship with a pervasive developmental disorder.

It should be noted that psychotic conditions may be aggravated when users exhibit comorbidities related to mood, anxiety or depression disorders (Kaplan & Sadock, 1997; APA, 2004).

The frequency of psychosis in PLWHA tends to be higher than in the general population, with prevalences varying between 0.5% and 15%. The psychotic conditions observed in PLWHA occur more frequently in advanced stages of the disease. Their development may be associated with prior psychiatric disorders, the use of psychoactive substances (alcohol and/or other drugs), autoimmune diseases, systemic lupus erythematosus, central nervous system infections and neoplasms, as well as the use of antiretroviral drugs (Robinson-Papp, Elliott & Simpson, 2009; Tennille et al., 2009).

The following table lists drugs that may be related to the development of psychotic conditions in PLWHA (Sewell, 1996, adapted).

DRUGS THAT MAY CAUSE PSYCHOTIC SYMPTOMS

ANTI-INFECTIOUS DRUGS

Aciclovir → Auditory and visual hallucinations
Cephalosporines → Paranoia
Dapsone → Hallucinations
Ethionamide → Hallucinations
Isoniazid → Hallucinations
Pentamidine → Hallucinations
Thiabendazole → Hallucinations
Zidovudine → Mania and psychosis
Efavirenz → Psychosis

ANTINEOPLASTIC DRUGS

Vincristine → Visual hallucinations

OTHERS

Amantadine → Visual hallucinations
Barbiturates → Hallucinations
Corticosteroids → Hallucinations

The treatment of psychotic disorders in PLWHA does not differ from the treatment offered to the general population except for the risk of drug interactions and the side effects of neuroleptic drugs. The most frequently used antipsychotic drugs are: haloperidol, risperidone and olanzapine. In patients who have already developed psychoses, efavirenz should be used with caution.

4.5 Delirium and dementia

Delirium is characterized by attention disorders and cognitive alterations that develop over a short period of time. Onset is usually abrupt and has a fluctuating course, affecting levels of consciousness and cognitive capacity. Delirium is associated with an organic etiology and has been described in cases of dementia and aseptic (or linfomonocitary) meningitis; it may develop during seroconversion, with a tendency toward complete remission.

The table below lists criteria for the diagnosis of delirium, according to the American Psychiatric Association (2004).

Criteria for the diagnosis of delirium (APA, 2004, adapted):

1. Altered level of consciousness, with reduced ability to direct, focus and maintain attention.
2. Altered cognition or development of perception disturbances that are not explained better by dementia that is pre-existing, established or evolving.
3. Onset occurs abruptly over a short period of time (hours or days) with a tendency to fluctuate during the day.
4. There is evidence in the patient's medical history, and in the results of the physical or laboratory exams, that the disturbance is caused by direct physiologic consequences of a general medical condition.

Hospitalized PLWHA who exhibit hypoxia, malnutrition, cryptococcal meningitis, systemic infections, tumors or intracranial abscesses and metabolic disorders or who use anti-infectious agents (e.g., aciclovir, amphotericin-B and pentamidine) or psychotropic drugs are at a greater risk of developing delirium than PLWHA who do not have these pathologies. The treatment of delirium requires hospitalization, immediate medical attention and referral by a healthcare professional or healthcare center (Breitbart et al., 1996; Ferrando & Freyberg, 2008).

A diagnosis of delirium may be aided by the Mini-Mental State Examination (MEEM) (Appendix A) (Folstein, Folstein & McHugh, 1975), or by electroencephalogram (EEG).

Dementia is characterized by multiple cognitive deficits that include memory impairment. Dementia, when associated with AIDS, is also called AIDS dementia complex (ADC), or subacute encephalitis, and develops from insults to the central nervous system caused directly by HIV.

In general, dementia develops during a later stage in the evolution of AIDS, although a case has been described where the HIV infection presented as a profile of dementia (Dilley et al., 2005; Wright et al., 2009).

Let us imagine a case of dementia in a patient who has been HIV-positive for 18 years.

> *Fabio, 45 years old, HIV-positive for 18 years, started to notice that he was missing appointments and kept forgetting what he had to do during the day. During a routine appointment, he told the specialist that he was depressed. He liked going for a run late in the afternoon and noticed that his legs felt weak during this activity; he finally gave up running. He was also doing badly in college: he could not concentrate in class, had difficulty understanding the teacher, and was not able to study by himself. The doctor diagnosed dementia in its early stage.*

The lack of concentration and diminished muscle strength in the patient's lower limbs were the symptoms that led the doctor to suspect dementia. Having knowledge of symptoms and the use of diagnostic tools can aid the diagnosis of dementia in its early stages.

The clinical manifestations suggest predominantly subcortical involvement, characterized by impairment of memory and concentration, slowed movements, apathy, diminished initiative and a tendency for social isolation. Other manifestations, such as depression, irritability, emotional instability and agitation, occur less frequently. The most common motor signs are impaired motor coordination, decreased strength in limbs, hypertonia and hyperreflexia.

The stages of ADC vary from 0 (normal), 0.5 (subclinical), 1 (mild), 2 (moderate), 3 (severe) to 4 (end stage). In this system of classification, clinical descriptions range from the absence of impairment of cognitive or motor functions to increased impairment at work, a decreased capacity to perform the activities of daily life, or even major intellectual incapacity (difficulty following the news or maintaining a conversation) and motor difficulties (for example, inability to walk unassisted). In stage 4, there may be aphasia (inability to speak), paraparesis (reduced sensitivity in lower limbs), or paraplegia (reduced strength of lower limbs) accompanied by urinary or fecal incontinence (Price et al., 1988).

It should be pointed out that when the cognitive decline occurs gradually, symptoms may be due to the use of alcohol or other drugs or the presence of depression, opportunistic diseases or other comorbidities.

It is estimated that up to 20% of people with AIDS develop dementia during the course of the disease; however, its prevalence depends on when ARVT is begun, age of user, anemia, constitutional symptoms, depression, cognitive and motor deficits, and coinfections. However, the introduction of ARVT has reduced the incidence of ADC in the last 10 years. A study conducted in San Francisco, CA, USA, showed that, in 1991, the prevalence of dementia among the HIV-positive was 3.71%, decreasing to 0.24% in 2003 (Dilley et al., 2005). The use of AZT and other antiretroviral drugs appears to prevent the development of dementia in PLWHA (Atkinson & Grant, 1994; Wright et al., 2009).

Because the direct action of the HIV in the central nervous system has a central role in ADC, ARVT must be developed with ARV drugs that cross the blood–brain barrier, as is the case with zidovudine (AZT) (Carvalhal, 2003; Wright et al., 2009). In addition to AZT, nevirapine and efavirenz may be used as alternatives when designing drug regimens for reaching therapeutic concentrations in the central nervous system (Wright et al., 2009).

ARVT has also contributed to an increase in the life expectancy of patients with ADC (Kandanearatchi, Williams & Everall, 2003). Average survival times after ADC diagnosis increased from 11.9 months in 1993–1995 to 48.2 months in 1996–2000, with the introduction of high-potency ARVT (Dore et al., 2003).

It is important to point out that, today, ADC has become more common in users with higher LT-CD4+ counts than during the era before the advent of high-potency antiretroviral therapy.

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Chapter 5

Integral healthcare possibilities for PLWHA

Illustration: MBS

This chapter addresses mental health care interventions oriented toward HIV/AIDS Specialized Healthcare Centers (SAEs) and Counseling and Testing Centers (CTAs) which they can design and implement in their daily work routines.

It is important to point out that stigmatization and the chronic nature of seropositivity, along with possible adverse side effects of treatment, are factors that increase the emotional and psychological vulnerabilities of PLWHA (Almeida & Labronici, 2007; CFP, 2008).

Therefore, healthcare team actions that are based on reception and extended clinical practices strengthen observation and identification of issues – through active listening and bonding processes – and the provision of integral healthcare support to users.

5.1 Psychological problems are not mental disorders

As we emphasized in Chapters 2 and 4, psychological problems are not mental disorders, and the absence of a mental disease is not synonymous with mental health. We reaffirm that the development of healthcare activities directed at physical and mental health at SAEs needs to be based on SUS's principles of equity, universality, integrality, interdisciplinarity and humanization (Brazil, 2004), and should be guided by a multi-dimensional and complex understanding of the health–sickness process that does not restrict or limit the concept of health to biologic and physical aspects (Reis, 1999; CFP, 2008) but rather characterizes it as the promotion of mental health and the prevention of psychological problems.

With regard to the offer of activities in the field of mental health, there are three possibilities:

a. Promotion and prevention campaigns directed toward all users of the service;
b. Specific healthcare actions, conducted by professionals such as psychologists and psychiatrists, or healthcare professionals who have been trained to perform interventions for identified demands;

c. Actions developed by other services offered by SUS's specialized mental healthcare network such as the Psychosocial Support Centers (CAPS) I, II or III, Children Support Centers, and Alcohol and Drug Rehabilitation Centers, among other healthcare institutions.

The actions described in items a and b should be favored by SAEs in their individual and collective interventions, and will be described in this chapter. In relation to the possibilities indicated in item c, we should point out that the Brazilian policies for mental health have enabled the implementation of a network of services for people diagnosed with severe mental disorders, integrated by SAEs through matrix support for the elaboration of therapeutic projects. From this point of view, although SAEs have teams with psychology and psychiatry professionals, integration with the municipality's mental health network (e.g., CAPS, Therapeutic Residence Services, social and cultural centers and general hospitals) is essential. This topic will be discussed in Chapter 7.

It should also be said that the quality of the follow-up of HIV-positive users with severe mental disorders implies, among other factors, going beyond the integration of mental health specialized services, and the construction of close ties with primary healthcare centers, family healthcare teams, oral healthcare centers, social assistance reference centers and general hospitals, with the purpose of ensuring institutional co-responsibility for care and connecting the user to integral healthcare. Included here are intra-sectorial groups (by means of the referral and counter-referral mechanisms established at SUS) and inter-sectorial groups, built on the perspectives of the locale (schools, NGOs, community associations, social centers).

The concept of the extended clinic – an approach centered on real people and their concrete experiences, while viewing the disease as part of this context and encouraging user's autonomy and self-care skills (Campos & Amaral, 2007) – is a reference for the debate on the modalities of healthcare offered by SAEs, and points to the impact of these actions on users' mental health, based on two fundamental aspects which are analyzed below.

5.2 Therapeutic effects of healthcare actions and theoretical–methodological standards

Several of the services provided by SAEs, such as reception, psycho-social evaluation, and social and support groups, may have *therapeutic effects* for PLWHA, playing a prevention role when they address aspects related to seropositivity, which may cause, for example, worry, anxiety, fear and sadness. Appointments that provide active listening and do not limit themselves to physical health aspects can have favorable repercussions on the emotional and psychological levels of users.

It should be emphasized that these actions – which provide *therapeutic effects* on mental health – do not qualify as psychotherapy. *Psychotherapy* is an intervention that uses psychological methods and techniques to achieve specific goals, such as self-knowledge and improved interpersonal relationships, and treatment of mental disorders (depression or anxiety, for example). Users seek out psychotherapy due to needs that are based on a range of reasons over the life of the user, and the user should be referred to a qualified professional with specialist training in this field.

The theoretical–methodological standards that guide professional practices, especially those of psychologists and psychiatrists, tend to be diversified as a function of their training and specialized qualifications. This diversity needs to be respected because it reflects state-of-the-art psychological science and various theoretical–epistemological orientations. Studies indicate that the bonds and mutual trust established between the healthcare professional and the user are more relevant for therapeutic efficacy than the theoretical orientation adopted by the professional (Ingersoll; Heckman, 2005).

5.3 Discontinuity versus continuity of the healthcare process

There are situations in which the psychological and/or psychiatric evaluation is carried out due to a request by the user's family or from the healthcare team, but an intervention does not always take place.

Prescriptive referral is a common situation and occurs when the professional identifies a need for a psychological or psychosocial consultation and decides to refer the patient without discussing the procedure with the user. The weakness of designing a therapeutic plan without the participation of the user causes misunderstandings and a refusal to acknowledge the decision made by the healthcare professional: *Why was I referred, to whom and for what?* The probability of non-adhesion to therapy or not going to the referral appointment are extremely high, a situation that is conducive to missing opportunities for timely healthcare and for the creation of bonds, thus increasing the user's vulnerabilities.

The moment and the conditions in which psychological and/or emotional problems appear during the medical and psychosocial evaluation are peculiarities that require distinct interventions and referrals in order to achieve effective approaches and solutions. We need to define whether the user's psychological and/or emotional difficulties develop after the diagnosis and are associated with living with HIV/AIDS, or whether they have been aggravated by this condition, as well as whether the onset was before or after learning of serological status. For example, an HIV-positive person with symptoms of anxiety, who has a history of anxiety disorders in his/her adult life, including psychiatric or psychological treatments, may require medical and psychosocial procedures different from those needed for people who are experiencing the first episode of anxiety in their lives as a result of learning of the HIV-infection diagnosis.

In some situations, the manner in which the work processes, the daily assignment of tasks and the responsibilities of the healthcare team are structured (as well as communication failures between the team and the user) may cause an interruption in assistance and compromise integral healthcare. See the following example: after an evaluation process, the psychologist diagnoses depression, informs the user of this diagnosis, and negotiates a weekly appointment with a psychologist, emphasizing its importance. The psychologist also states that he/she will call the next week to arrange the next appointment, but fails to do so. This failure to contact the user and the user's depression collaborate in contributing to his/her failure to seek psychological assistance; it disrupts the bond and the relationship of trust. The frustrated expectations of professional support disrupt the care process and increases the user's vulnerabilities by causing the user to feel abandoned, and the depression may be aggravated with negative effects on self-care, adhesion and quality of life.

Actions offered to users may have positive consequences for users' mental health, as long as users' needs are respected and the care process is continuous. They provide a better understanding of the disease and treatment and help to build a space that favors communication between professionals and users, and encourages the expression of feelings and thoughts about sero-positive status and the dimensions of life affected by this condition.

5.4 Modalities of intervention in HIV/AIDS specialized services

There is a range of interventions or (inter)actions that may be offered at SAEs which are powerful tools for producing positive results on the mental health of users. They are didactically classified into three large categories: individual care, couples or family care, and group care.

It should be pointed out that this manual does not contain an exhaustive list of all possible actions that may be offered, since the composition of teams, the organizational structure, and the specificities of professional qualification may increase or reduce healthcare alternatives. Also, we highlight that therapeutic projects for PLWHA may have various configurations depending on the clinical conditions of the user, the possibilities for team actions, and the installed capacity (available spaces for appointments, doctor's offices, rooms for group work, etc.), as well as the adhesion of users to the modalities of assistance.

1) Individual care

Individual accompaniment developed by SAE's multi-professional teams may be offered to all users, and comprises reception, counseling, pre- and post-testing, reproductive health counseling, guidance activities, individual assistance with a focus on adhesion, and psychological or psychosocial evaluation, among others. Appointments characterized as treatment involve social, psychological and/or psychiatric interventions, psychotherapeutic follow-up, peer reviews, etc.

Individual accompaniment is offered more frequently at healthcare centers and appears to be preferred in contexts of chronic illnesses with stigmatizing characteristics, such as HIV/AIDS, because it ensure the confidentiality of the user's condition and what is being done for it. Operational aspects – such as the ability to negotiate appointments (days and times) – also favor adhesion and individual assistance.

It is crucial to point out that individualized care, in any modality, requires a user-centered focus in order to guarantee the exclusive attention of the professional to subjective factors and personal issues, protecting users' privacy and facilitating the elaboration of individualized therapeutic plans.

> In the context of mental healthcare, individualized care is an action directed at the psychosocial, psychological, and/or emotional difficulties of PLWHA who exhibit various degrees of severity and compromised health; it also presupposes a user-centered focus that includes their social and subjective issues.

2) Couples and family care

The provision of healthcare to couples occurs when the user's sexual partner participates in the intervention. Throughout life, couples tend to review their relationship, discuss their difficulties and conflicts, and reorganize their daily roles. With the advent of a chronic disease, the need to review the relationship may become more evident; in the case of HIV/AIDS, given the possibility of sexual transmission of the disease, various issues impact marital life and sexuality.

An approach to couples care means that there are certain specifics and must take into account whether both are seropositive or whether they are serodiscordant. Serodiscordant couples often report reactions of anxiety and fear of infecting the seronegative partner, causing great harm to the quality of their sex life. Issues related to reproductive rights are also usually relevant demands among these couples (Polejack & Costa, 2002).

In this assistance modality, one aspect that influences the problem at hand is whether or not the conjugal partnership was established before or after the HIV diagnosis. In cases where the partnership was established before the diagnosis, it is common to feel hurt, resentful and guilty, to have doubts about marital fidelity or about the sexual orientation of the partner, to have reduced sexual desire, and to be afraid of HIV reinfection through sexual relations.

Therefore, the requirements for providing care to couples are different and may necessitate fewer or more frequent appointments in order to cover topics such as the adoption of safe sex practices, reproductive choices, the desire to bear children, adapting to the diagnosis and living with HIV, problems with the sexuality of one of the partners or of the couple, and relationships with their original families or their social connections, among others.

An ethical principle of great relevance must be taken into account in this modality of intervention: the consent of both parties must be obtained prior to couples assistance being conducted, and include their commitment to keeping information confidential. If one of the partners does not agree to couples therapy, the healthcare professional must respect the user's decision and attempt to receive clarification of the reasons and motivation for the refusal.

Providing assistance to families in the HIV/AIDS context means that family members or persons with whom the user maintains significant social relationships are targeted by the approach, and this results in diverse appointments, depending on the demands presented by the user and his/her network. The number of people being assisted may vary depending on the issue being worked on, the connections between the members of the group, and the family or social context of the user. Another aspect is that the appointment may or not include the user, although the same ethical concerns mentioned before must be observed: prior consent and confidentiality and restricting questions to issues that will be the targets of the intervention.

Appointments with an educational focus are common and have the objective of facilitating the family's and/or social network's support for the PLWHA and discussing attitudes of prejudice and discrimination, by sharing information that improves knowledge of seropositivity, forms of transmission, treatments and other aspects of living with HIV/AIDS. Often, this type of accompaniment is of short duration and may occur in a single meeting.

Another frequent topic is that of how family members may constitute an effective social support system, helping the user with aspects he/she is having trouble dealing with. Examples are adhesion to treatment and self-care, a situation where the family, together with the user, may receive joint counseling on how to negotiate daily behaviors that are conducive to adhesion. With the consent of the user, family members may participate more actively, for example, in reminding and monitoring the use of medication and in becoming co-participants in the care process (Polejack, 2001; Brazil, 2008).

Attitudes of prejudice and discrimination, violations of human rights, and disregard for users' autonomy within the family context are frequent topics during appointments. In these cases (based on reported complaints), approaching the family must be preceded by individualized and repeated invitations to them to participate in the appointments, with the purpose of bringing the family members closer to the healthcare team. The principles of reception – active listening and bonding – are also applicable here and facilitate the active participation of family members.

The healthcare professional should also take the needs for support presented by the family into consideration. Learning of a new diagnosis or changes in the health condition of one of the members may have great emotional impact on or cause psychological problems in other members. When faced with this situation, the family member becomes the focus of the intervention, and it is important to provide a space for listening and acknowledging their feelings, questions and support needs.

3) Group care

The development of group activities has some advantages when compared to individualized care, from the point of view of public health (White & Freeman, 2003), as listed below.

a. Interactions among members may facilitate the establishment of mutual bonds and strengthen users' support network.
b. There may be a therapeutic component when a participant identifies him/herself with another who is experiencing similar difficulties.
c. There is also a prevention component as a result of empathy, understanding and learning due to experiences one participant has gone through but the other has not.
d. Attention can be given to a larger number of people in a single space and using a similar period of time when compared to individualized assistance, decreasing the cost of intervention.
e.

The greatest advantage of group work is the exchange of experiences among peers who have faced similar challenges and difficulties; it also strengthens feelings of belonging and of social support.

Group interventions may vary in relation to the number of meetings, duration of activities, frequency (weekly, fortnightly, monthly), theoretical–methodological or pedagogical aspects, and characteristics of participants (homogeneous or heterogeneous groups).

Another feature of group work relates to the possibility of new members joining the group. The modality that allows for the continuous entry of new participants is characterized as "open," that is, people may come and go whenever they like. A "closed" group begins with the users who are registered and who adhere to the activity and does not permit new participants to come in during its course. The open modality may be exemplified by groups that conduct fortnightly meetings, and attendance depends on the interest and availability of participants. Thus, some people attend the meetings regularly, while others will be less assiduous, and others will come to only one session and never return. This feature should not become a hindrance to achieving the group's goals; therefore, professionals conducting activities need to keep in mind the high rate of turn over when scheduling them.

In the other modality (a "closed" group), participants know that the group will be formed with a pre-determined composition and that no new participant will be permitted to join after activities have begun. The closed group modality tends to produce better cohesion and bonding among participants when compared to open groups. An example of this would be a group composed of HIV-positive individuals with lipodystrophy, structured as a workshop, with 6 two-hour weekly meetings planned, offered to 10 participants who must have already signed up.

The challenges in conducting group activities may come from issues raised by users, by healthcare professionals, or by the team. The stigmatizing aspects that still affect PLWHA are a challenge for users' adhesion to group activities related to HIV/AIDS (Brazil, 2008). Many PLWHA refuse to participate in group activities for fear of breaches of confidentiality or of meeting someone they know. In order to minimize this difficulty, participants must agree on the criteria and ethical aspects related to the confidentiality of the group work. It should also be observed that the invitation to and awareness raising of group assistance should respect the user's level of readiness and preparedness to engage in group activities.

From the point of view of the team professionals, challenges may include insufficiently trained personnel for conducting or facilitating group work, the absence of a suitable physical space, or insufficient time for conducting activities. Taking these aspects into consideration, strategies should be implemented to minimize these limitations, allowing for a greater offering of group activities at SAEs.

Group activities allow for:

> "...the construction of a motivational environment for treatment through sharing challenges and the search for alternatives for overcoming them. They permit the construction of bonds, of reception, of respect for differences, and reinforce self-esteem and self-care." (Brazil, 2008, p. 99)

5.4.1 Group modalities

Without intending to provide an exhaustive list of all possible group interventions that can be implemented by healthcare services, we would like to describe some of the more general activities that are more frequently used at SAEs, taking into consideration groups of people in various contexts of psychological or psychosocial vulnerability.

Adhesion groups

Difficulties in adhering to treatment and care may be associated with feelings of worry, guilt, anxiety, depression and denial of serological status. Other difficulties may be related to the user's social life, such as unemployment, exclusion, extreme poverty, or the use of ARV drugs in the work place. Therefore, providing a space for active listening, dialogue and reflection, which permits the identification of reasons for non-adherence and the development of strategies to face and overcome the situation, may reduce negative feelings and stress associated with these difficulties, with a positive impact on mental health.

Adhesion groups are usually open and are conducted by professionals from the healthcare team or NGOs, and have adhesion to treatment as a priority. As described in the *Manual for PLWHA Adhesion to Treatment*:

> "...addressing adhesion within a group is a practice that is based on collective work, on interaction, and dialogue. It has an informative, reflective, and supportive nature, and the purpose is to identify difficulties, discuss possibilities, and find appropriate solutions to individual and collective problems that are compromising adhesion to treatment." (Brazil, 2008, p. 98)

Conversation circles

A conversation circle is a community-based strategy that provides spaces for dialogue, usually in open groups (people may join or leave at any time), and tend to be held relatively infrequently. The objectives may be comprised of discussions on topics such as adhesion, sexuality, reproductive rights and lipodystrophy, among others. Services may set up schedules and topics in advance, then disseminate them to users and encourage their participation.

Flexible and punctual conversation circles can favor the participation of people who are afraid of group activities, eventually stimulating users to participate in other group modalities in the future. They may be conducted by healthcare professionals or by NGO workers.

Community-based group therapy

Community-based group therapy may be described as:

> "...a tool that permits the construction of networks of social solidarity for promoting life and mobilizing the resources and competencies of individuals, families and communities. Community-based therapy proposes to care for the community's health in public spaces, valuing prevention and understanding that prevention means, above all, encouraging the group to use their creativity and to construct their present and their future using their own resources." (Instituto Ser, 2010)

One of the characteristics of community-based therapy is that each meeting deals with a specific topic that emerges from the group itself, proposed by one or more participants. The "problem situation," presented by a member and chosen by the group, is the starting point of the therapy. The facilitator tries to encourage and facilitate the sharing of experiences, allowing for the construction of social support networks. The question that triggers group reflection is: "Who has experienced something similar and what did you do to solve the problem?"

Next, the sharing of experiences is promoted, showing possible strategies for overcoming the difficulties and sufferings of daily life and allowing the community to find their own solutions to the problems that a person, family or public services were not able to resolve by themselves. Each meeting is self-contained, and its participants are free to choose whether or not to attend subsequent meetings.

The number of groups within SUS's healthcare services that conduct meetings using community-based therapy as a reference is growing. In order to conduct these meetings and their activities, specially trained facilitators are required. Since the characteristics of the theoretical–methodological standards for community-based therapy are applied, any user may participate in the groups and, in principle, there are no criteria for exclusion.

Mutual-help groups

Mutual-help groups are characterized by reciprocal and voluntary exchanges of resources and services for the benefit of the parties involved. They are homogeneous groups in the sense that all participants have the same problems or are experiencing similar health conditions or life situations (Barros, 1997). The number of groups using this framework has been growing in the field of healthcare and HIV/AIDS, especially in NGOs, making highly relevant contributions in addressing various issues that affect the life of PLWHA.

In general, mutual-help group activities are conducted by the participants themselves and they aim to, among other objectives, facilitate the exchange of experiences, improve the level of knowledge of HIV/AIDS, promote relationships, and scale-up social support networks. Since this modality is organized and managed by PLWHA themselves, these activities may constitute spaces for empowerment and strengthening of autonomy.

Waiting room activities

Waiting-room activities may come in a great variety of formats depending on the specific aspects of the healthcare services and the team. While users wait for their appointments, the activities are carried out in a brief and dynamic way (from 20 to 60 minutes) with a focus on specific topics (there is no sequence to the meetings).

These activities make good use of the time that users spend in the centers, promote health education, and sensitize the public to participate in other modalities of group or even individualized activities.

Due to their nature, health education topics are commonly addressed, but may not necessarily focus on diseases. Facilitators may use materials or audiovisual resources such as pamphlets, videos or films. Topics such as the rights of users, general health issues, and diet and nutrition can be developed in the waiting room. One aspect to be observed is that, since the activity occurs without the prior consent of the user, ethical issues are very important and need to be taken into account, and "forcing" the user to participate must be avoided. It is fundamental to maintain an environment in which everyone is allowed to speak, those who wish to remain silent are respected, and users are free to leave the environment if they choose.

How can healthcare teams implement these actions?

The modalities of assistance in the field of mental health offered at SAEs for couples, families, individuals or groups (and in particular those modalities that require specialist training) vary depending on user profiles and needs and the training and availability of healthcare professionals. Due to eventual limitations, efforts must be made to improve the team's qualifications and enable them to implement the activities. Some of the alternatives in this regard are worth mentioning:

1. Provide or organize continuing education activities in healthcare, with the purpose of having discussions about the opportunities and limits identified in daily work practice and of qualifying the healthcare team to enable it to intervene in mental health care.
2. Ensure that teams are comprised of a range of various specialists, including psychologists, social workers and psychiatrists.
3. Provide matrix support for supervised mental health care to team members, with the input and advice of specialists who may be unaffiliated with the institution.
4. Strengthen partnerships with other healthcare networks in municipalities, non-governmental organizations and universities qualified to provide mental health assistance.
5. Conduct periodic meetings in which experiences can be exchanged and cases discussed in an ethical manner while ensuring the confidentiality of the information presented.

The elaboration of an individualized therapy plan (ITP) is an example of how a team can implement actions to promote mental health and integral healthcare for users, whether for an individual, group or family.

Designing an ITP requires a comprehensive evaluation of the user, taking into consideration biological, psychological and social dimensions in all their unique aspects (as well as knowledge about the support network), which should be the result of collective discussions by the multi-disciplinary team, with matrix support when necessary. This tool is indicated for more complex situations and is a variation on clinical case discussions.

ITPs favor the workings of an integrated team and an appreciation of other factors in addition to the diagnosis and pharmaceutical treatment of the user; they permit the opinions of all professionals involved with the care to be heard, facilitating a better comprehension of the user and the user's specific requirements, while aiding in defining proposed courses of action. Also, ITPs allow evaluations to be performed by team members who have different points of view and different knowledge bases with regard to the user, which means that care strategies will be designed that better fit the needs of the user and the user's ability to adhere to treatment.

Promoting true inter-disciplinarity, contributing to the efficacy of interventions, requires facilitating communication between the various specialists and healthcare professionals, respecting their differences and embracing their diversity. This also means that sharing of responsibilities for cases and for practical and systematic actions should be encouraged, in accordance with the unique aspects of each therapeutic plan. Although ITPs are developed with the shared inputs of team members and users, it is worth pointing out that the user should have a professional who is designated to be the user's point of contact – this should be the person with whom the user has most bonded and has a relationship of trust. This professional should be in charge of providing guidance for the changes needed during the process of the provision of care and in helping the user with the required follow-up appointments. Thus, there are countless possibilities and modalities of actions for promoting mental health and integral healthcare for PLWHA. Any decision for which intervention appears to be the most appropriate course of action for a user, family or group should be discussed among team members and negotiated with the user, making case management more consistent and efficient within the context of integrality.

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Chapter 6

Delivery of healthcare by teams

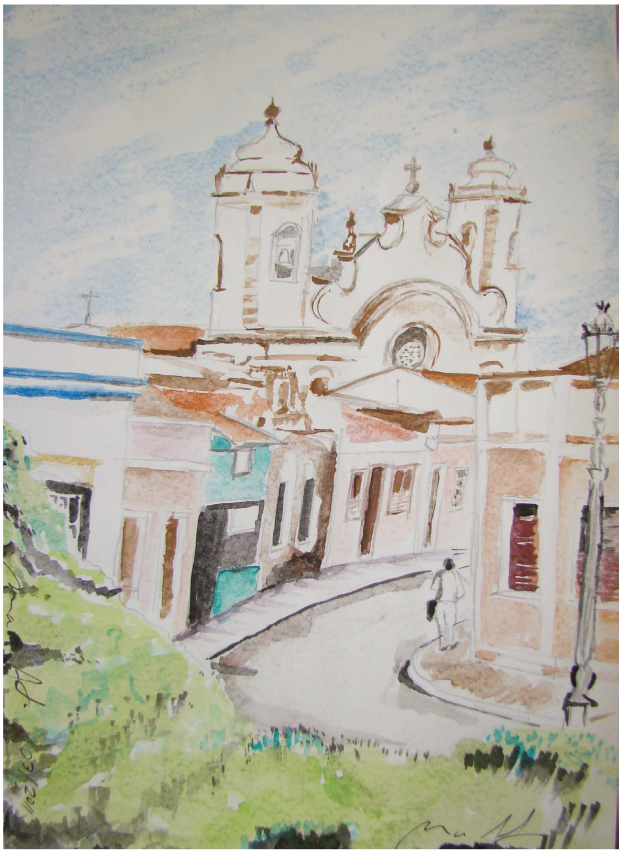

Illustration: Marco Antonio

In the preceding chapters, we proposed reflections on the various aspects of healthcare at the interface between HIV/AIDS and mental health. These two conditions and their interactions have led to rethinking about the dimensions of care, revising the role of healthcare teams, and investing in public policies that prioritize quality of care.

During the past few decades, HIV/AIDS and mental health have brought to the fore issues of subjectivity and complexity in the health–sickness process and various dimensions that should be considered in healthcare practices. The manner in which a professional deals with users is guided by the ideas he or she has about the health–sickness process, and it is often difficult to separate feelings and personal beliefs from professional practice. However, is this the best path? Should we separate who we are from what we do?

On the contrary. Our professional role is part of who we are and how we think and feel as individuals, and recognizing this impacts our professional performance, just as our professional experiences enrich our personal lives and broaden our view of the world.

In the common sense of its meaning, taking care of one's health means "paying attention to or providing interventions for an individual or group, by involving a set of technically-oriented procedures in order to achieve the success of a particular treatment" (Ballarin, Carvalho & Ferigato, 2009, p. 219). But is it limited to this? The complexity of the health–sickness process has given rise to several reflections about the various dimensions of caregiving and courses of action in healthcare. Caregiving also means respecting values, embracing diversity, taking feelings into account and expanding listening.

Healthcare depends fundamentally on the quality of the bonds that are established. Various authors have shown that the result of a therapeutic process is strongly influenced by the quality of professional–user interactions, even when a diagnosis and a well-designed treatment are available (Tourette-Turgis & Rebillon, 2000, 2002; Moraes & Ongaro in Teixeira, 2006; Straub, 2007), i.e., healthcare needs to take into consideration the social and emotional dimensions as well as the biological dimension.

Therefore, it is not possible to discuss bonding without talking about relationships, and this is possible only if there are at least two subjects. In this case, we are talking about the relationship between the healthcare professional (and his/her team) and the user. They are both subjects of this relationship and, as such, their subjective and emotional dimensions need to be considered. A bond is constructed in a relationship by means of subjectivity and affect and the ability to put oneself in the place of the other and respect the other's emotions, beliefs, ideas and feelings. Without question, technical knowledge is important for a healthcare professional, but the creation of bonds is an even more important tool.

Thus, we invite you to reflect on mental health factors during your professional practice, the importance of working together, and strategies for strengthening the team, as well as support for the healthcare professional.

6.1 How to manage psychological stress in healthcare professionals

Circumstances related to living with HIV/AIDS and the issues that arise from patients' psychological suffering and mental disorders can also impact the healthcare professional. Life situations shared by users may result in the professional's own suffering and feelings of helplessness, insecurity, fear and uncertainty about the best measures to be adopted. This psychological stress may cause the professional to become ill.

In addition, relationships among healthcare team members may create a work environment that strengthens or weakens the professional's ability to handle these stresses and his or her daily routine. Various studies have sought to better understand the impact of stress on professionals whose activities require emotional involvement (Gil-Monte, Peiró & Valcárcel, 1998; Carlotto, 2002; Gil-Monte, 2002; Borges, Argolo & Baker, 2006). In the last three decades, one of the most studied problems in workers is the so-called *burnout syndrome*. According to Maslach (1994), this condition develops in response to chronic sources of emotional and interpersonal stress in the work place. The term was first coined in 1974 by psychiatrist Herbert J. Freudenber, and, at first, it related to experiences of exhaustion which had, as their main cause, individual factors. Various researchers have become interested in this subject and, over the years, the concept has expanded; today, burnout syndrome is understood as "a process that develops through interactions between characteristics of the work environment and personal characteristics" (Borges et al., 2002, p. 191).

In this sense, it is a problem that primarily affects professionals who work in environments where there are difficulties in communication between team members and a lack of empathy for the worker's subjectivities. There are various studies describing this syndrome in healthcare and education professionals, but the problem is not limited to these contexts. The exercising of these occupations implies relationships with users that are permeated with ambiguities, such as that of walking a fine line between professional and personal involvement while caring for the other (Borges et al., 2002).

For Gil-Monte, Peiró and Valcárcel (1998: in Gil-Monte, 2002), the most common manifestations of this syndrome are concerned with the notion of professional failure, including negative attitudes towards one's professional role (e.g., a lack of self-realization at work) allied with a feeling of emotional exhaustion and negative attitudes and feelings towards coworkers (depersonalization of the other). The principal consequences of burnout are apathy, dehumanization and a process of alienation, resulting in absenteeism, health problems and a desire to leave one's profession.

When a professional stops caring about the feelings and suffering of the other, it is a sign that the professional is becoming ill.

How can this illness be prevented? How does one care for the caregiver in the midst of so many other demands?

In order to prevent this, it is necessary to consider a variety of means which may range from appreciation of the professional – with extensive actions in training and human resources – to small support actions in each service. Paying attention to the feelings and behaviors caused by stress and being worn-out, using creativity and flexibility when facing the adversities of daily work, developing a reflective and solidary attitude in the team's relationships, and seeking institutional and/or professional support are measures that strengthen relationships and protect individuals from stress and falling ill. It is not always easy to work in teams, but the team has a central role in the creation of healthier work environments.

Considering the mental health of health workers, from the point of view of management and public policies, suggests taking into account the factors described above (Borges et al., 2002; Brazil, 2007); however, it also means providing adequate working conditions and infrastructure, preventing the weakening of connections at work, not having a lack of professionals or an overload of activities, and promoting continuous education of the teams, among others.

These topics will be discussed in more detail below.

6.2 Interdisciplinary team work: challenges and methodologies

Team work is a type of group work characterized by a reciprocal relationship between technical interventions and the interactions of the group's agents. However, the theoretical literature on team work shows that there is a predominance of technical approaches in which professional work is understood to be a set of attributions, tasks or activities (Peduzzi, 2001; Teixeira, 2006; Deslandes & Mitre, 2009).

In addition to problems with their health, users who seek out healthcare bring with them their subjective dimensions and life histories, both of which may influence the health–sickness process and thus should be taken into account for health promotion strategies. However, the fragmented organization of the work process is not conducive to an integral understanding of the user because each professional is responsible for only one aspect of all of the related tasks. According to Merhy (2003), an illusory association between quality of care and requesting of exams, prescription of drugs and the arrangement of appointments with specialized professionals is created. Alternatives means of organizing the work processes around the user are not discussed or prioritized, and this is one of the main issues that need to be dealt with in order to bring about change in healthcare services.

The importance of interdisciplinary work for the quality of healthcare has been debated and reinforced by several authors, who point to the various advantages for both the professional and the user (Teixeira, 2006; Brazil, 2008). To better understand the types of organizations that favor interdisciplinarity, we discuss below a few important concepts.

Disciplinarity is understood as related to a homogeneous field of study, with well-defined boundaries, such as, for example, psychology, nursing, medicine and nutrition, with a notion of identity that perpetuates and constantly updates norms.

Multidisciplinarity suggests the juxtaposition of diverse disciplines. It does not necessarily presuppose team work and integration. For example, we may set up a service with professionals with different specialties who assist the same users but who do not establish a joint and integrated work process.

On the other hand, interdisciplinarity proposes overcoming the disciplinary boundaries in order to transform the view of the world, of ourselves and of reality, with the purpose of extrapolating the disciplinary view, expanding the interdependent space, and mediating the way we see and act in the world.

Interdisciplinary team work arises as a partial response to a new way of seeing, thinking and acting in the field of healthcare resulting from the challenges presented by various diseases. It is defined by:

> "…the degree of interaction between disciplines and the intensity of exchanges among specialists; from this interactive process, all the disciplines are enriched. It is not enough to borrow elements from other disciplines, but rather, to compare, judge and incorporate these elements in the production of a modified discipline." (Costa, 2007, p. 109)

A good example of interdisciplinary performance is the development of an individual therapeutic plan, taking into account that the care required may go beyond what one discipline would normally understand as the prescribed treatment.

Interdisciplinarity is an invitation to create a new field of joint and collective knowledge, in which the challenge is to transform fragmented actions into integrated work with the purpose of providing the best care to the other and to oneself (Saintrain & Vieira, 2008).

To consider the performance of an interdisciplinary team is to consider a set of professional categories, with specific training and differentiated theoretical frameworks. Team members use their respective technical knowledge to contribute to the user's health. We need to remember that they are all actors and subjects in a process of caregiving built on relationships. More than doctors, psychologists, social workers, nurses, nutritionists, physiotherapists and assistants, they are subjects: people who have feelings, experiences and worldviews whose interactions are much richer than just the exercise of technical knowledge. However, only rarely does a team ponder the challenge of discussing the broader objective and subjective reality of healthcare work (Peduzzi, 2001).

Thus, in order to cope with this first challenge, we need to comprehend the role of each team member and respect the limits of action in order to propose the necessary exchanges among the various specialties. It is fundamental that each professional understand his or her functionalities and the objectives of all activities, seeking strategies that permit communication between team members and users and their families. The role of each professional is not always clearly defined during a case. For this reason, it is important that spaces be created to permit the exchange of experiences and information, and that each professional share with the team his or her proposed approach for the situation at hand.

The second challenge is to implement strategies that facilitate communication among team members and between the team and users. According to Deslandes and Mitre (2009), we need to understand that communication processes go beyond issuing and understanding informative content. In this sense, it is fundamental to develop a space for the sharing of information, experiences, feelings and emotions. This space should allow room for conflicting opinions, but its principal objective should be to maintain acknowledgement of and respect for the opinions of others, attempting to comprehend the other's view of the world. The author also points out the importance of learning how to communicate, which translates into the wish to know the stories, motivations, desires and expectations of the other.

> "The challenge is to recognize, learn and negotiate with another who is not our mirror, but another person, who is imbued with three states: an individual with rights, an individual with the autonomy to make choices, and an individual with a cultural heritage that gives him or her a framework for their identity in his or her social group." (Deslandes & Mitre, 2009, p. 647)

The third challenge is to broaden embracing and actively listening to other members of the team, as described in Chapter 3. Listening means permitting the other to express him- or herself and to share what he or she thinks and feels. But how can we understand this embracing and active listening within the team? We can exemplify the possibility of including aspects related to the feelings and reactions of the professionals during the discussion of cases, going beyond the technical issues involved.

6.3 Strategies for team care

The National Humanization Policy (NHP) presents guiding principles that value subjective and social dimensions in all SUS's care and management activities by considering workers and users as partners in the healthcare process. By various means, it seeks to strengthen the multi-professional team, fostering transversality and group work (Brazil, 2004).

As discussed in the preceding chapters, the NHP uses the theories and concepts of extended clinical practice, reception and groupality, which are meant to provide a foundation for health practices and to help reflection on team work.

The concept of extended clinical practice underlies team work and how one relates to the service, users and the team itself. It is important to realize that the expanded concept of clinical assistance begins with changing the way we establish relationships with users and team members, valuing the building of connections as forms of intervention and healthcare. Reception, on the other hand, represents an attitude towards relationships and is not a location or a moment during the flow of the provision of care. In this sense, it is important to begin to exercise this welcoming posture with our team mates, trying to learn and respect their ideas and feelings, and being willing to share ours.

Groupality is based on the establishment of relationships and the building of connections. It is not possible to create ties without affection, and it is not possible to nurture affection without getting to know something or someone. We need to remember that we often spend more time with our team mates than with other family or social groups, and sometimes we know very little about them. Investing in the approximation and in the construction of spaces for listening and co-management means investing not only in the quality of the service or healthcare that we provide to users, but principally in the quality of the relationships and health of the team itself.

> "Groupality is an experience that is not limited to a group of individuals; neither can it be taken as a unit or immutable identity. It is a collective or a multiplicity of elements (users, workers, managers, families, etc.) in which members are both transformed and are agents of transformation, comprising a network of connections in which the processes of subjectivities and healthcare are realized." (Brazil, 2004, p. 41)

6.4 Organizing service routines

We present here forms of organization of a unit's routines which, in addition to facilitating care and building connections with users, also crucially benefit the mental health of the caregiving team.

Each service has a reality and a type of demand, and different ways that a team may organize itself and function. Therefore, the suggestions below must be considered with regard to the need for transformation and the reality of each team. They may be implemented gradually and must be understood to be practical strategies that facilitate the organization of the team for collective action.

6.4.1 The process of reception

It is important that a team be able to:

- Work with flexible schedules, including the ability to reschedule appointments or fit in users who require urgent care.
- Determine when a case is urgent. When is it necessary to prioritize a user during provision of care? There must be a clear understanding of the maximum time a user can wait before being seen, depending on need.
- Change the timing of appointments according to the user's profile (extended work period). This attitude facilitates access to services and benefits the team because it generates better results in achieving goals and improves the health conditions of the population assisted.

6.4.2 Team meetings

An important step towards the organization of collective work, one that values healthcare directed at team members as well, is the implementation of spaces for the exchange of information and permanent dialogue.

According to Campos,

> "…a meeting is a space for dialogue, and an atmosphere of rapport where everyone has a say and a right to their opinions… Creating a fraternal atmosphere for the exchange of opinions, associated with the objectivity of meetings, usually requires a learning process for all parties involved and is the first task for any team." (2000, p. 183)

Meeting times should be established by the team – they are usually held weekly or fortnightly, allowing for all professionals to prepare themselves to bring up topics they feel are most pertinent. Having a predetermined schedule facilitates the organization of daily routines so that all team members are present at the meetings.

Meetings may be of a scientific nature (updates, readings and joint discussions) and/or be an exchange of experiences (discussion of cases, sharing of procedures). Outside this theoretical classification of meeting formats, it is possible for a single meeting to have its time divided between various topics. It is also important for the professionals involved with the cases or topics for discussion to have sufficient time for preparing their presentations in advance, as this improves the group discussion process.

In-depth discussion of the importance of confidentiality and ethics in daily activities is important when we consider the subjective dimension of the workers involved. Also, when sharing case histories, it is crucial that the team pay close attention to the continuity of care provided to user, in spite of the differing types of information that may have been exchanged among professionals, or the plan previously developed by the team.

6.4.3 Individualized therapeutic plans

Every healthcare practice is permeated by the "nurturing" dimension whose objective is to produce processes of talking and listening, mediating relationships with the users' subjective worlds and how they construct their health needs, reception and bonding relationships, ethical attitudes, and the integration of knowledge for designing therapeutic plans (Merhy in Teixeira, 2006, p. 48).

As presented in the preceding chapter, discussions on the design and accompaniment of an Individualized Therapeutic Plan (ITP) may be an excellent time for valuing healthcare team professionals. The perception and recognition that they all have relevance in the process – even when, at certain times, some of the team members may exercise a greater leadership role or more creativity than others – is gradually reinforced by the interdependence among team members and, also, by the importance of integrating the various intervention resources that each professional has.

In order for ITP discussion meetings to function properly, it is necessary to have an atmosphere conducive for dialogue, in which everyone learns to talk and listen (including to critiques), taking into account the difficulties and limitations of the team and of each member, while ensuring that institutional hierarchical issues do not hinder freedom of expression. This is the only way to develop new courses of action and to promote healthcare. A matrix process, based on the continuous supervision of on-going cases, is also an alternative means of getting the most out of a team of professionals, and may be conducted by a professional from the team or a guest from other reference services. Interlocution may help in comprehending a specific topic and aid in the design of the ITP. As the team begins to recognize its own limitations and difficulties – an essential condition for discovering and overcoming them – it can ask for help and transform this space into a process of continuous learning. Using interconsulting as a model – facilitating communication among the various professionals who assist the same user – is also another alternative for the team.

As we have seen, there are many alternatives that can be created and/or explored in order to improve relationships among team members and between the team and the user. Everyone who chooses to work in healthcare has a commitment and desire to make a difference in someone's life. With small changes, we can achieve great results, always remembering that strengthening the team is also a form of care.

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Chapter 7

The challenges of network healthcare: integrating policies, programs and actions

Illustration: Lafayette

7.1 Policies on Mental Health, Alcohol and Other Drugs

The National Policy for Mental Health, Alcohol and Other Drugs (whose directives are based on Law 10216/2011) has gained international recognition due to its innovative nature. Its main purpose is to restructure psychiatric healthcare in Brazil, substituting the previous model centered on hospital assistance with a model based on regional and community-based healthcare. The new model highlights users' leadership, autonomy and their co-responsibility with managers, workers and families, all with a view toward improving quality of life and affective and social relationships.

The effective implementation of these policies requires the expansion of a substitutive network with a focus on responsible healthcare as well as on social and family reintegration. This restructuring process of mental healthcare involves transformations in practices, knowledge and values, and cultural and social paradigms.

7.2 How can this process be changed in our daily routine?

In the preceding chapters, we presented concepts that integrate the directives of the Policy for Mental Health, Alcohol and Other Drugs, which are fundamental for transformations to occur in practice. Talking about humanized assistance means talking about active listening. The healthcare professional needs to be attentive to issues that go beyond the disease and its diagnosis, taking into consideration the life stories, dreams, fears and the affective family and social relationships of the individual who seeks attention and care. The exercise of active listening must be viewed as essential for the elaboration of an **individualized therapeutic plan** that incorporates the concept of viewing subjects as active participants in their own treatment and follow-up, with emphasis on their autonomy and civil rights.

When we talk about **interdisciplinarity**, we introduce the concept of collective construction and the exchange of knowledge and experiences among professionals, without a hierarchy of knowledge. The greater the diversity of professional qualifications and the more spaces there are for these exchanges to occur, the greater the possibility of providing integral healthcare, which results from the synergy of different perspectives, experiences and knowledge with the purpose of constructing a practice that responds to the real needs of individuals.

This concept leads to others that are equally important, such as intersectoriality and co-responsibility, which are not easy to achieve because they imply team work and the sharing of responsibilities with a clear definition of roles and agreement on commitments.

In practice, institutional and personal contacts are needed. These contacts develop from visits and meetings to recognize and become acquainted with the professionals and services provided by potential partners; it is also possible and often necessary to integrate joint discussions of cases with those in other fields, which may often result in the re-orientation of the therapeutic plan.

7.3 How is the delivery of mental health care organized?

Mental health care is conducted by various services and institutions, such as the Psychosocial Community Centers (CAPS) (in their various modalities: I, II, III, Children, Alcohol and Drugs; see Appendix B); mental health outpatient facilities; Therapeutic Residential Services; beds for integral healthcare in general hospitals; reference hospital services that provide care to people with mental disorders and with needs due to the use of alcohol and drugs (SHRad); and the Social Community Centers; as well as the initiatives to generate jobs and income, and the mental health campaigns in primary healthcare (Brazil, 2004).

Recently, through Ordinance/GM No. 3088 (published on December 23, 2011), the Psychosocial Assistance Network was established with the goals of creating, extending and integrating points of care for people with psychological problems or mental disorders or those with needs related to the use of crack cocaine, alcohol and other drugs.

In this network, CAPS plays a strategic role in psychiatric reform by offering mental health care to the population of the region to which they are connected, conducting clinical follow-up and promoting social campaigns for the reintegration of users through access to work, leisure and civil rights, and the strengthening of family and community bonds.

CAPSs are characterized as places of reference and treatment for people who present mental disorders, psychoses, severe neuroses or disorders due to the use of or addiction to alcohol and other drugs, as well as other conditions whose gravity and/or persistence require users to stay in a facility that provides individualized intensive care, community support and health promotion.

What differentiates the healthcare provided by CAPS from others is their psychosocial focus, which gives users a leadership role in their treatment, respecting individual peculiarities and favoring civil rights. Assistance is not limited to the mental disorder or disease, but focuses on the subject and seeks the provision of integral healthcare to users.

In addition to CAPS, there are other institutions for mental healthcare: beds for integral healthcare at CAPS III, in general hospitals and at Reference Hospital Services, as well as hospices or shelters that provide support during crises, avoiding admissions and re-admissions to psychiatric hospitals.

There are campaigns developed by multidisciplinary teams in Mobile Clinics concerning the lines of care for alcohol and other drug users as well as their families (in addition to CAPSad and beds reserved for emergency care or short-term care in the general hospitals and SHRad). These actions include harm reduction activities in the services as well as in the streets.

For the social reintegration of people with mental disorders who have been discharged from long-term admissions to psychiatric hospitals (PH), there is the “Return Home” Program, which is comprised of financial aid for psychosocial rehabilitation, and the Therapeutic Residential Services, which is housing in the community designed for caring for people whose social bonds and family ties need to be reestablished.

The Social and Cultural Centers, the Initiatives to Generate Job Opportunities and Income of the Brazilian Mental Health and Solidarity Economy Network, and the Users, Families and Friends Associations are devices that help promote social inclusion, expansion of autonomy and improvements in life conditions, income, culture, leisure and education of people with mental disorders and/or with problems due to use of alcohol and other drugs, as well as their families.

Campaigns for mental health are also developed in primary care, following the model of the care network based on defined territories and transversal actions, integrated with other specific policies that aim to establish positive receptions and bonding. Because of their proximity to families and communities, primary care teams represent a strategic resource for combating diseases linked to the abusive use of alcohol and drugs, in addition to various other forms of psychological problems.

A great number of people with mild mental disorders are assisted in primary care centers (psychosomatic complaints, depression, alcohol and drug abuse, benzodiazepine addiction, mild anxiety disorders, etc.).

Support for primary care is given by matrix teams whose aim is to offer technical support for mental health care through supervision, joint appointments and specific assistance, as well as participation in training initiatives. These activities may also be conducted by bringing together the professionals working at Counseling and Testing Centers (CTA), for example, and those working in mental health institutions.

Mental Health teams are comprised of professionals with various qualifications: psychiatrists, nurses, psychologists, social workers, occupational therapists, educators/teachers and others, as well as professionals without higher education, such as technicians and/or nursing assistants. The issues of team horizontality and daily use of different knowledge bases are part of the service routine and should reflect a manner of working in which there is no dominance of one specific set of knowledge.

Welcoming users, developing individualized therapeutic projects with a focus on promoting psychosocial rehabilitation, sharing spaces, creating innovative answers for unexpected problems, developing positive environments and ensuring civil rights and respect for the other, as well as fighting stigma and active listening, are all premises that should guide team work.

The therapeutic plan, as well as the frequency with which users access services and therapeutic facilities, depends on variables such as the degree of the psychological problem or damage and the social and family support network, among others, and should always include the participation of users in the construction of the plan. The important thing is to have, as a goal, the greatest possible autonomy for users, in the process of the construction/reconstruction of social bonds.

Often, the work conducted by the CAPS team is that of deconstructing the need for treatment. However, this deconstruction does not imply a lack of commitment to the person seeking assistance. It is indispensable for team members to commit themselves, whenever necessary, to the referral of users to other services – such as Primary Healthcare Centers, Family Healthcare Centers, Specialized Attention Services, Counseling and Testing Centers, etc. – so that they may meet the very real needs of the person who is suffering and accompany them. Thus, everyone who comes to the service will be heard and his/her demands will be valued, although these demands may not necessarily translate into being taken up by the service.

7.4 Service providers specialized in HIV/AIDS

Counseling and Testing Centers (CTA) are health services whose mission is to promote equity and access to counseling and diagnosis of HIV, hepatitis B and C, and syphilis, as well as the prevention of these and other STDs. Their activities prioritize segments of the population that are at greater vulnerability, respecting human rights, willingness to accept treatment and integral healthcare, with no territorial limitations.

In order to promote users' access to CTA activities, it is important for the CTAs to remain open during the day (mornings and afternoons) and, whenever possible, offer extended hours in the evenings or on the weekend.

The CTAs should offer all tests necessary for the serological diagnosis of HIV, syphilis and hepatitis B, C and D. In addition to traditional testing methodologies, all CTAs should use rapid testing for the diagnosis of HIV. The implementation of rapid tests at CTAs should contribute, above all, to the expansion of access to HIV diagnosis to populations at most risk of HIV infection.

Counseling is a prevention activity that allows the provision of individualized attention. It also represents an important component of the HIV, syphilis and viral hepatitis diagnostic process. Counseling at the CTAs should not be restricted to pre- or post-testing nor to providing assistance to people who seek diagnosis. Counseling before testing should be offered to all CTA's users. This stage comprises receiving the user, establishing bonds, mapping vulnerabilities and providing guidance about the test. Users have the right to choose whether or not they want to receive pre-test counseling, regardless of the diagnostic methodology used (rapid or conventional test). This does not mean suspending reception and dialog about the motivation for getting tested, the methodology to be used, or the expectations about the results. For CTAs that offer different types of testing, the user has the right to choose what method to be used.

In view of the need to adequately handle users' reactions when faced with the diagnosis, as well as to reiterate prevention guidance, the delivery of all test results performed at the CTAs, regardless of whether they are positive or negative, must be accompanied by individual post-test counseling.

CTAs provide the following services to people living with HIV and to carriers of viral hepatitis: effective referral of cases to reference services, establishing mechanisms that guarantee counter-referral; follow-up of users after the diagnosis whenever they are not being assisted at reference centers in order to contribute to a better process of assimilation and assignment of meaning to the new serological status as well as adhesion to care and treatment; and provision of counseling sessions for seroconcordant and serodiscordant couples.

The evaluation of specific vulnerabilities to HIV and hepatitis B and C, related to the use of alcohol and other drugs, must be included in all actions developed by CTAs. These centers should also address these issues from the perspective of harm reduction and adaptation of prevention guidelines during counseling, depending on the type of drug used. Harm reduction kits (whose composition should be adjusted according to the reality of drug use in the context where the CTA is inserted), as well as other essential inputs (male and female condoms, lubricants), must be available at the centers and during outreach activities.

The CTA must be seen to be part of the public health network and should participate in the discussion and decision-making spheres such as in local health committees and councils. The permanent dialogue of CTA teams with other healthcare teams – in primary or specialized healthcare units – contributes to the provision of integral healthcare.

CTAs have accumulated experience and knowledge and can contribute to the training of healthcare professionals and other players, in areas such as counseling and others, defined in accordance with their abilities.

The **Specialized Healthcare Services** (*Serviços de Atenção Especializada*: SAE) are outpatient facilities offering integral healthcare to PLWHA.

The multi-professional team should have at least one clinical physician and/or infectious disease specialist, a nurse, a nursing assistant and/or technician, a social worker and a psychologist.

The service should be characterized by ease of access for the population in the municipality's geographical area (taking into consideration the road network and distribution of the population, among other factors) as well as inside the health unit itself (it should use good signage and be easy to get around in, among other factors).

The activities in the center should be directed at providing integral healthcare by the multi-professional team and prioritizing outpatient assistance (individualized or collective) to people with STDs, HIV/AIDS and viral hepatitis. The main activities of the SAEs are:

- Prevention and promotion of quality of life, including: offering STDs and HIV/AIDS diagnosis with individualized and/or collective pre- and post-test counseling; offering prevention inputs in general, encouraging the use of condoms; promotion of harm reduction campaigns such as interventions for drug and alcohol users; risk evaluations for the introduction of post-sexual exposure prophylaxis; offering activities directed at adhesion to treatment; promotion of activities in the waiting room; promotion of activities for improving the quality of life of PLWHA; promotion of mental health campaigns by the multi-professional team, with a focus on humanizing reception, assistance and active listening of users; approaching partners and offering diagnostic testing for serodiscordant couples; and offering rapid tests for HIV, syphilis and hepatitis B and C.
- Clinical and psychosocial assistance to people living with HIV/AIDS, including: constructing Individualized Therapeutic Plans (with the participation of the user); conducting family planning, including strategies for reducing the risk of sexual and vertical transmission of HIV during family planning, guaranteeing sexual and reproductive rights of PLWHA; conducting initial laboratory and clinical approaches; recommending primary and secondary prophylaxis for opportunistic infections (OIs) and STDs; prescribing and managing ARVT, including the prevention and monitoring of adverse events and recognition and management of therapeutic failure; clinical and laboratory diagnoses, as well as management of comorbidities; conducting TB testing; maintaining established contacts for referrals for facial filling as a treatment for lipoatrophy; providing psychological follow up (individualized or in groups, to encourage self-care); post-exposure and occupational prophylaxis; offering needed guidance on health legislation (for PLWHA) and social assistance.

- Maintenance of references for diagnostic, laboratory and other support services, ensuring the conduction of CD4/CD8 cell counts, viral load measurements, and genotyping tests, as well as other exams relevant to the case.
- Offering assistance in situations of occupational accidents and sexual abuse, or maintenance of the references established for these situations.
- Offering assistance during all stages of the health–sickness process, in an interdisciplinary manner, guaranteeing the referral and counter-referrals organized by RAS.
- Offering integral healthcare for STDs.
- Offering integral healthcare to viral hepatitis carriers, depending on the organization of the local Healthcare Network, including clinical and laboratory assistance.
- Conduct epidemiological surveillance activities related to STDs, AIDS, viral hepatitis and co-infections.

At SAEs, the essential inputs are: male and female condoms, lubricants, ARV (when there is an associated Drug Dispensing Unit (*Unidade de Dispensação de Medicamentos*: UDM), prophylaxis inputs, and treatments for opportunistic infections as well as STDs, harm reduction kits and educational materials.

The **Reference and Training Centers** (*Centros de Referência e Treinamento*: CRT) are reference units having a multiplicity of knowledge, technical information, and healthcare team specialists in various sub-specialties that provide integral healthcare to people with STDs and HIV/AIDS.

The minimum composition of the CRT is: infectious disease specialists including at least one reference doctor in genotyping; a gynecologist and obstetrician; a nurse; a nursing assistant and/or technician; a social worker; a psychologist; a nutritionist; and a dental surgeon. In regions where there is demand, the inclusion of a pediatrician in the multi-professional team is recommended.

According to the criteria established by Ordinance No. 1, issued jointly by the Secretariat of Healthcare Attention and the Secretariat of Health Surveillance (published January 20, 2009; Brazil, 2009), CRTs must also conduct facial filling and, therefore, the team should include a qualified dermatologist and/or plastic surgeon for conducting this procedure.

Ideally, the extended team required for conducting the service's reference activities should also include a physiotherapist, a phonoaudiologist and a physical education professional.

The activities developed at the Reference and Training Centers are the same as those conducted by SAEs, but also include:

- Follow up prenatal care of HIV-positive pregnant women;
- Prevention and treatment of dental problems;
- Nutritional approaches for preventing and treating adverse events;
- Physical evaluation and counseling on the practice of physical exercises.

In addition to these considerations, it should be noted that healthcare activities for PLWHA are all organized around the concept of team–user, so that care is not doctor centered.

This is one of the great challenges of the CRTs, in addition to having to establish an effective **Health Assistance Network** (*Rede de Atenção à Saúde*: RAS). This network must base its work on the organization of health campaigns and services with differing technological densities which, when integrated via technical, logistic and management support systems, are capable of ensuring integral healthcare.

RAS's objective is to promote systematic integration of health actions and services, providing continuous, responsible, humanized, integral and quality healthcare. It is characterized by the construction of horizontal relationships between the points of care, by the centrality of the health needs of the population, by assuming responsibility for continuous and integral healthcare, by multi-professional care, and by sharing the objectives and commitments with sanitary and economic results. These considerations are described in detail in Ordinance 4279, published on December 30, 2010 (Brazil, 2010).

It should be noted that the training and operationalization of this Healthcare Network is carried out by healthcare professionals; in this case, SAE's professionals.

In their daily practice, teams must be cognizant of the flowcharts of the users' referrals and the healthcare network available:

- CAPS I, II and III
- CAPSi
- CAPSad, CAPSad III
- Hospital beds
- Therapeutic Residential Services
- Shelters
- Primary healthcare
- CTA

Other support networks to which the SAEs should relate, such as NGOs, teaching and professional training institutions, churches or other religious spaces, cooperatives, and cultural centers, are also of great importance for the integration of PLWHA.

The involvement of healthcare professionals in all these activities may seem complex, but it is fundamental for the provision of integral healthcare to PLWHA. It is important that each professional seek, in his or her field of expertise, training in the specificities of providing healthcare to PLWHA, and that they share this knowledge with the team during their case discussions and exchanges of experiences.

7.5 Strengthening partnerships

One must remember that the STDs and HIV/AIDS specialized services, as well as mental healthcare services, must be included in an integrated network of healthcare that proposes to offer a continuum of assistance. Thus, partnerships with Healthcare Programs, especially services that specialize in STDs, AIDS and viral hepatitis, contribute fundamentally to promoting quality integral healthcare that is inclusive.

The strengthened integration of the services that comprise the healthcare network will be conducive to the exchange of information and guidelines regarding managing and providing the specific care requested by clients. This care may be provided within the service (and may be focused on illnesses resulting from HIV/AIDS or those due to mental disorders and the use of alcohol and other drugs) or by services from other programs, thus providing truly integral and integrated healthcare.

For some time there has already been collaboration between the Mental Health Coordination and the Department of STDs, AIDS and Viral Hepatitis. An example of this is the joint effort to incorporate harm reduction strategies for alcohol and other drugs users in the general health care centers, STDs and AIDS specialized services, and in the Psychosocial Community Centers (CAPS). Another example of collaboration between different areas is the support, through joint directives, for projects proposed by NGOs, universities, and state and municipal offices. One such directive established the development of the PESSOAS Project (a multi-centric national study of the seroprevalence of HIV, syphilis and viral hepatitis B and C infections in public institutions of mental healthcare), a successful partnership whose objective was to determine the prevalence of these diseases among people assisted by psychiatric hospitals and substitutive services (CAPS); describe their sociodemographic and behavioral profile, risk conditions and healthcare; and evaluate the structure of the services (hospitals and CAPS).

This study pointed to important issues for reflection by managers and presented some background information for the implementation of specific actions by the Mental Health Coordination and the Department of STDs, AIDS and Viral Hepatitis. Some of these issues related to the need to develop sex education campaigns and programs and STDs/AIDS prevention programs, with training of professionals in these two program areas, taking into account the peculiarities and vulnerabilities of people with mental disorders, ensuring integrated and integral attention based on the establishment of partnerships among the respective services and investing in a truly effective referral and counter-referral system.

These actions are guided by principles common to both fields: reception, social inclusion, guarantee of civil rights, intersectoriality, and combating stigma and discrimination.

Another important interface should be established with primary healthcare, one which demands broad intervention in diverse areas in order to have a positive effect on the quality of life of the population; in short, for this interface to be efficient, effective and resolutive, there is the need for various types of expertise.

A fundamental condition for creating a favorable atmosphere between the health service and the target population is maintaining close ties with the community. Thus, Family Healthcare is the priority point of entry for this hierarchical and regionalized health system and has been influencing a movement for re-orienting SUS's healthcare model. With the objective of supporting the insertion of the Family Health Strategy in the service network and expanding the coverage of Primary Healthcare actions – as well as their problem-solving skills – the Ministry of Health created the Nucleus for Support to Family Health (NASF) via Ordinance GM No. 154 (originally published on January 24, 2008, and republished on March 4, 2008; Brazil, 2008).

NASF should be comprised of teams made up of professionals from various fields in order to work together with professionals from the Family Healthcare Teams (FHTs), sharing health practices in the territories where the FHTs and NASF are registered.

The NAST team and the FHTs create spaces of discussion for managing care. Thus, NASF does not constitute a point of entry to services, but provides support to family healthcare teams and has, as its core principles: accountability, shared management and support for the coordinated healthcare that is to be provided to families.

The methodology prioritized in the operation of this healthcare strategy implies a need to promote integration with other healthcare units and to understand the user in his or her totality.

7.6 How should the challenges of integration be faced?

For facing the challenges of improving integration, there are certain strategic steps:

1. Get to know the territory, i.e., map out the network of services, programs and initiatives offered by the government as well as by civil society. This knowledge will permit all the available resources to be used when designing individualized therapeutic plans.
2. Integrate the various points of the network by means of visits during which information, experiences and proposed courses of actions can be shared, with a view toward creating partnerships.
3. Keep technical knowledge up to date, propose certification and continuing education courses and in-service training, learn about the differing characteristics of users in each service and region, and pay attention to the cultural and social features of the territory.
4. Establish flowcharts so that partnerships can be effective, working as a reference for other services.

When we consider that healthcare results from multiple social policies meant to promote quality of life, we can see that the challenging task of integrating the various sectors in order to solve problems becomes a strategy that translates into intersectoriality.

What is intersectoriality, after all?

Intersectoriality, as a management practice, permits the creation of shared spaces among institutions and various sectors that actuate in the promotion of health (education, work and employment, housing, culture and others). Intersectoriality views citizens in their entirety (their individual and collective needs), permitting the formulation and implementation of public policies that will have a positive impact on the population's health. Thus, intersectoriality ensures the integrality of course of action because its practice requires integration, connections, complementary actions, horizontal relations between partners, and interdependence of services.

Therefore, everyone, and in particular healthcare professionals, has an important role in combating stigma and discrimination, and changing the feelings and meanings that have become ingrained in society.

Currently, the Ministry of Health has been investing in the strengthening of SUS. An example is Decree No. 7,508 (published on June 28, 2011), bringing Law No. 8,080 (dated September 19, 1990; Brazil, 1990, 2011) into conformity, which governs the organizations of the Brazilian Public Health System (SUS), health planning, healthcare, and inter-federative integration. The objective was to give more transparency to SUS management, guiding the definition of responsibilities in relation to health services and actions, the standardization of health regions, and the improvement of inter-federative relations via the institution of the Organization Contract for Public Health (*Contrato Organizativo da Ação Pública de Saúde*: COAP) as a mechanism for strengthening the Health Pact, from the perspective of guaranteeing the effectiveness of the citizen's right to healthcare.

This decree is a tool whose main purpose is to facilitate the effective integration of health services. Thus, the consolidation of this strategy and the daily challenges faced by healthcare professionals has made it possible for SUS to establish itself as a universal right to healthcare of Brazilian citizens.

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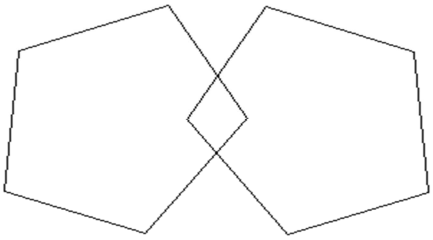
Appendices

Illustration: Vivian Lee

Appendix A: The Mini Mental State Exam (MMSE)

Questions	Points
1. "What year is this? What season? What day? What month?"	5
2. "Where are we? Which state? Country? City? Neighborhood or hospital? Which floor?"	5
3. Name three objects (e.g., car, vase, window), saying them in one-second intervals. Then, ask the patient to repeat them for you. Repeat the answer until the individual learns all three words (5 attempts).	3
4. Serial sevens: "Subtract 7 from 100; subtract 7 from this number," etc. After 5 answers, take a break. Alternative: "Spell 'world' backwards."	5
5. Ask the patient to name the three objects learned in question 3.	3
6. Show a pen and a watch. Ask the patient to name the objects as you show them.	2
7. Ask the patient to repeat: "No if's, and's or but's."	1
8. Ask the patient to follow these instructions: "Pick up a sheet of paper with your right hand. Fold it in half with two hands. Place the paper on the floor."	3
9. Ask the patient to read and do the following: "Close your eyes."	1
10. Ask the patient to write a sentence of their own choosing.	1
11. Ask the patient to copy the following drawing: 	1
Total score (maximum: 30 points)	

Source: Folstein et al. (1975); Bertolucci et al. (1994).

Appendix B: Types of Psychosocial Community Centers (CAPS)

CAPS I: Municipalities with between 20,000 and 70,000 inhabitants

- Provides daily service for users residing in the specified region who exhibit persistent and severe mental disorders and disorders caused by the use of and addiction to alcohol and other drugs.
- Open from 8:00 a.m. to 6:00 p.m., Monday through Friday.

CAPS II: Municipalities with between 70,000 and 200,000 inhabitants

- Provides daily service for users residing in the specified region who exhibit persistent and severe mental disorders and disorders due to the use of and addiction to alcohol and other drugs.
- Open from 8:00 a.m. to 6:00 p.m., Monday through Friday.
- Some stay open until 9:00 p.m.

CAPS III: Municipalities with more than 200,000 inhabitants

- Provides day and evening service, 7 days a week, for users residing in the specified region who exhibit persistent and severe mental disorders and disorders due to the use of and addiction to alcohol and other drugs.
- Open 24 hours a day, including holidays and weekends.
- Upon publication of Ordinance 130 (dated January 26, 2012), CAPS III may also provide services for crack cocaine, alcohol and other drug users, and in these cases is referred to as CAPSad III.

CAPSi: Municipalities with more than 200,000 inhabitants

- Provides service daily for children and adolescents with mental disorders or disorders due to the use of and addiction to alcohol and other drugs.
- Open from 8:00 a.m. to 6:00 p.m., Monday through Friday.
- Some stay open until 9:00 p.m.

CAPSad: Municipalities with more than 100,000 inhabitants

- Provides service daily for alcohol and drug users with disorders due to the use of and addiction to alcohol and other drugs.
- This type of CAPS has beds exclusively for detoxification treatment.
- Open from 8:00 a.m. to 6:00 p.m., Monday through Friday.
- Some stay open until 9:00 p.m.

Note: for the implementation of services, other criteria may be taken into account in addition to the number of inhabitants, e.g., epidemiological criteria.
Source: Ordinance/GM 336, February 19, 2002; Ordinance 130, January 26, 2012.

Appendix C: Art Workshops at São Paulo's CRT-STDS

All illustrations for this manual were produced at art workshops focused on HIV/AIDS patients registered at São Paulo's Reference and Training Center in STDs and AIDS. These art workshops began in 1997 following an interdisciplinary proposal between the Psychology Service and the Social Service.

Today, the workshops are divided into two groups: The Canvas Painting Workshops and the Watercolor Workshops. They are both conducted at the studio of the Lasar Segall Museum and involve the voluntary participation of psychologists, social workers and visual artists, in partnership with the Museum. Located near the Institution, the Museum provides a more suitable environment and is greatly valued by the service's users as a space for art and culture.

To participate in the workshops, users need only show interest in the activity; no prior knowledge of any art technique is required. Also, no one is excluded.

The purpose of these activities is essentially therapeutic: using art and painting techniques to promote better psychological balance, to improve self-esteem, creativity, socialization and social re-integration, and to generate income.

The workshops are conducted weekly, with 2.5-hour sessions; each workshop involves about twelve participants. The initial proposal is for users to produce an image by reproducing or creating it, thus stimulating their creativity.

Any adult user may attend the workshops. Those interested in participating are placed on a waiting list and are invited as openings become available.

During the year, in addition to weekly activities, the works produced are exhibited in various spaces within the CRT and other institutions. These works are offered for sale, and all monies go to the artists. Monitored field visits to museums in the city of São Paulo – as well as other activities that stimulate the group's socialization – are also promoted, with the objective of technical and cultural improvement.

The art works produced are also used to illustrate diverse CRT advertisements and publications.

Proposed goals are seen to be met when users realize that their potential is being valued during any of the stages of elaboration, production or conclusion of the art work. It should be noted that the symbolic construction itself is considered to be more important than the final result.

Techniques and group processes facilitate the expression of internal content, either through the medium of art or verbally among participants, encouraging the exchange of experiences among them.

The presence of mental health care professionals is essential for the workshops to function well. Their role is to be attentive to the process and to intervene, assuming the role of mediator, in situations involving difficulties and behaviors that may arise during the activity, as well as in intra- and inter-personal relationships. Currently, the professionals in charge of coordinating the workshops are: Fabiana Lo Bello, Laura H. Bugamelli, and Marisa F. Nakae.

Artist volunteers Lenira Lopez Romero and Rosa Higasi also have an important role, not only due to their artistic and technical skills, but also for their willingness to make themselves available for this work.