

The Double-Edged Sword: The Friction Between Community
HIV Support and Stigma in *Confissões de um soropositivo* and
its Implications within the Medical Discourse

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April 2022

Abstract:

Brazil is regularly noted for its exceptional HIV/AIDS epidemic response but despite this, Brazil also has a history of stigma regarding HIV. Today, stigma can have great impacts on individuals diagnosed with HIV and is one of the greatest barriers to HIV treatment. In the (2017) book *Confissões de um soropositivo* [Confessions of a seropositive], Léo Cezimbra outlines his experiences with HIV and describes the difficulties he faced after being diagnosed. By analyzing social and self-stigma and social support independently and then assessing their impact together within a concurrent space we reveal how together they can create tension for Cezimbra and negatively impact his ability to cope with. Thus, like a double-edged sword, the concurrent space where stigma and support overlap has a drastic impact on Cezimbra and leads him to socially withdraw, become distressed and frustrated. In some cases, support even acts within the concurrent space as a vector for stigma rooted in historical events. These findings support the notion that social understanding of HIV is well behind the advances in modern medicine and illustrate the need for HIV treatments to include support networks in the treatment process. It also highlights the need for education within support networks, to avoid the concurrence of support and stigma. These findings have implications in healthcare and allow us to reflect on potential external aspects and their impact on the success of a treatment regimen.

In the independently published book *Confissões de um soropositivo* [Confessions of a seropositive], the author Léo Cezimbra makes an account of his journey of being diagnosed with HIV in Recife Brazil, one of the cities with the highest prevalence of HIV in Brazil. He describes the HIV stigma that he faced and the critical supportive role that his family and friends played in his journey with HIV. His story begins in 1996, when at the age of 13 he first heard of HIV and was exposed to the stigmas associated with it. While growing up, he was constantly seeing HIV

being portrayed negatively on the news, he saw celebrities like Cazuza, the first publicly open HIV celebrity and advocate die. He also recalled watching movies like *Philadelphia* (1993), that depicted a seropositive lawyer as he died in agony from AIDS. While being exposed to negative perceptions of HIV during his teenage years, he developed a fear and internalized stigma around HIV similar to the stigma that existed in society. In this book, Cezimbra outlines the strong support and the stigma he experienced from his friends and family and the experiences of adapting to a life with HIV; this allows for a deeper discussion on the space where stigma and support coexist. Analysis of both the societal and self-stigma and Cezimbra's support networks in this text demonstrates not only a concurrent space where stigma and support overlap, but also the capacity for support itself to be a vector for stigma.

Before discussing HIV in the context of *Confissões de um soropositivo*, it is important to first explore what HIV is and its context in Brazil. HIV (human immunodeficiency virus) is a virus that targets the CD4 T-cells that make up the body's immune system. These cells are important for fighting disease and opportunistic infections. Without an early diagnosis and treatment of HIV, the virus continues to destroy the body's immune system by decreasing the number of CD4 T-cell cells. When the immune system CD4 T-cell count drops below 200 cells/mm³, HIV is said to have progressed to AIDS (acquired immunodeficiency syndrome). The normal CD4 T-cell count in a healthy adult is 500 to 1,200 cells/mm³ (Taylor 118). Weakening of the immune system can leave an individual with increased susceptibility to environmental bacteria, fungi, and other opportunistic infections. Eventually AIDS will lead to death. HIV can be contracted from transmission of bodily fluids like blood, seminal fluids, rectal fluids, vaginal fluids, and breast milk. Most commonly, HIV is transmitted via blood from sharing used needles with an HIV+ individual or through anal and vaginal sex with an HIV+ individual (Weiss 1273).

In Brazil, the dolutegravir drug based antiretroviral treatment (ART) for HIV was adopted in 2017 as the preferred first-line therapy and has been growing in global accessibility and affordability (Meireles 1665). Dolutegravir works by inhibiting the ability of the virus to replicate itself (Flexner 2021). The viral load of a HIV+ individual can reach around 50 000 copies/ml without treatment, with treatment it is possible to reduce the viral load to an undetectable amount within 3 to 6 months (Attia 1398). With an undetectable viral load, a HIV+ individual cannot transmit HIV through sex. With the advent of these treatments, HIV+ individuals can live a lifespan similar to that of the general population (Webel 364).

The Brazilian response to HIV is regularly noted as an impressive response (Okie 1977, Gómez 529, Gauri 47) where a total HIV government healthcare investment of US \$232 million resulted in 1.1 billion of savings and reduced HIV mortality by 50% over 7 years (Berkman 1162). Government provided healthcare system in Brazil along with the advances in HIV treatments have made getting treated for HIV a possibility for anyone, but despite this, individuals suffering from the condition don't always seek treatment. Discrimination arising from stigma has been identified as one of the greatest barriers to combating HIV in Brazil (Hoffmann 57). In the 1980s, an eruption of HIV in Brazil occurred shortly after the end of a fifteen-year military dictatorship (Valle 29). During this time Brazil became the country with the highest HIV prevalence in Latin America (Montano 61) and many advocacy groups like Grupo de Apoio à Prevenção à AIDS (GAPA), Associação Brasileira Interdisciplinar de AIDS (ABIA), Grupo Pela Vida (GPV) were founded by politically connected leaders who fought for access to HIV care (Valle 14). Their efforts impacted and shaped the medical system in Brazil which now provides free healthcare and HIV care at no cost. Through the onset of the Brazilian AIDS/HIV crisis in 1982 leading up to the 21st century, the face of HIV has changed drastically. What was

once a death sentence that primarily affected the LGBTQ community and was furthermore considered by society to be strictly a disease of that community (Silva 311), is now a treatable condition, and one that is seen across demographic bounds. Free government sponsored HIV programs and treatment developments have helped to turn the once deadly disease into a treatable one.

The most HIV affected groups in Brazil are female transgender sex workers (Costa 2534) followed by men who have sex with men (Malta 1). There has also been an increase in HIV prevalence among married women, particularly those of low-economic background (Parker “Sexuality”, 170) where the ratio of reported male HIV cases to female reported HIV cases of 23.5 to 1 in 1985 shifted to 1.7 to 1 in 2002 (Berkman 1162). Understanding how patients with HIV in Brazil are treated is important for understanding Cezimbra’s experiences in seeking HIV care in Brazil and the resources he had access to. HIV care is mainly undertaken and managed by the SUS (Sistema Unico de Saúde [Unified Health System]). The SUS is a government health system that has successfully made HIV treatment and ARV treatment accessible to all Brazilians. SUS provides HIV+ patients with counseling and ART at no cost, but due to demand and limited clinic hours in some remote regions, SUS clinics can have long wait times. Private clinics in Brazil can only offer greater accessibility for diagnoses but don’t have access to government produced ART drugs (Montenegro 2). For this reason, Cezimbra first travels to a private clinic and after receiving a positive test, travels to the SUS for treatment.

Along with social support, the two main types of stigma described within *Confissões de um soropositivo* are social stigma and self-stigma. To properly understand and analyze the two kinds of stigma, social support and the possible implications it had on Cezimbra’s life choices we must accurately define and contextualize both types of stigmas and social support. Social stigma

originates in society and can give rise to several social impacts for individuals with stigmatized identities. HIV social stigma can be defined as negative attitudes and beliefs toward people with HIV and it is often fuelled by myths and pre-existing biases towards HIV+ individuals. Social stigma affect's HIV+ individual's disclosure behavior, relationship with family, friends, and co-workers which interferes with their health-seeking behavior. Contraction of HIV can result in guilt and self-blame upon acquiring HIV as those who contract the virus may hold themselves responsible for the infection and socially withdraw (Dhaor 1). Social stigma is particularly evident when Cezimbra has to justify himself to family and friends. This happens when he is trying to convince his family that he is HIV+ and there was no mistake in the diagnostic test, when his friends continually insist on him accompanying them to the party despite his fragile health and when people he had intimate relationships with did not want to touch or kiss him after he revealed his HIV status. Overall, these instances represent the negative attitudes towards HIV that characterize social stigma and give rise to self-blame while interfering with Cezimbra's health-seeking behavior.

Self-stigma originates from social stigma and can have negative impacts similar to those of social stigma. HIV self-stigma is defined as when a person takes in the negative ideas in society about HIV+ individuals and apply it to themselves (Corrigan 192, Quinn 42). It can arise from the internalization of social stigma (Florum-Smith 157) or when an individual's fear of stigma is greater than what would otherwise be experienced (Hing 1664) and can result in feelings of shame, fear of disclosure, isolation, despair (Florum 155), less hope (Lysaker 193), less self-esteem (Fung, "Self-stigma" 97), and less self-efficacy (Fung, "Measuring" 410). Self-stigma negatively affects help seeking behavior (Barney 52) and undermines adherence to treatment recommendations (Fung, "Measuring" 97, Rintamaki 362). This is most evident when

Cezimbra internalizes the negativity he receives from friends and people he went on dates with who rejected him because of his HIV+ status and develops low self-esteem, fear of disclosure, isolation and low self-efficacy. He not only internalizes social stigma in the form of self-stigma but begins to develop anxiety and fear over social stigma greater than what he actually received leading him to be secretive of his status. Overall, he internalizes part of the social stigma he experiences and as a result begins to socially withdraw and fear disclosure of his HIV.

Throughout Cezimbra's journey in being diagnosed with HIV, he constantly relies on his family and friends for support. Social support can be defined as the physical and emotional comfort given to an individual by their family, friends and community. Social support for a person with HIV is critical for assisting with information seeking, providing medical support, giving validation, and encouraging perspective shifts (Brashers 307, Peterson 296). Cezimbra regularly describes his mothers and his sister's support. His mother supported him by encouraging to seek treatment and even booked him a doctor's appointment. His sister supported him by providing comfort when he was concerned about his lifespan after contracting HIV and by pushing him on when he felt he couldn't continue his ART medication routine because of the side effects he was experiencing. Overall, social support played a critical role from the moment he was diagnosed with HIV and without it, his journey with HIV would have been very different and he may never have sought or continued ART treatment.

Although social support generally has positive implications, it can occasionally act as a vector for stigma. This is particularly notable when Cezimbra's family tries to be supportive but instead ends up distressing Cezimbra as their support was based on the stigmatizing belief that he would die in less than two months. In such a situation social support actually carries with it stigma.

With self-stigma, an individual being aware of the presence of stigma within society impacts the individual even when not directly stigmatized, this can harm a person's self-esteem and self-efficacy (Corrigan 189). Social stigma and self-stigma are particularly notable when Cezimbra describes his experiences as a teenager. He notes how he was constantly immersed in negative narratives of HIV and how he developed a fear himself. After being diagnosed, he experienced social stigma from his family, friends and from himself in the form of self-stigma. He also describes how he was afraid of how people would perceive him with HIV and began socially withdrawing as a result. On the other hand, Cezimbra's success in combating HIV was heavily based on the social support he received after his HIV diagnosis. In Cezimbra's account, stigma and social support both play significant roles in how he copes with his HIV diagnoses. To fully understand the individual impacts of social stigma, self-stigma and social support it is important to isolate and analyze stigma independently from social support before addressing the combined impact of stigma and support within the concurrent space. Below we analyze social and self-stigma independently from social support before discussing their roles within the concurrent space.

As a teen, Cezimbra experienced a significant amount of societal HIV stigma in relation to his sexuality. In *Confissões de um soropositivo*, Cezimbra describes his experiences watching the movie *Philadelphia* where a lawyer dies a painful death as he combats AIDS and watching the media portray the body of the rockstar Cazuzza, the first HIV Brazilian celebrity HIV advocate, degrade and melt away as he slowly died from AIDS.

“Filadélfia” veio pra mim logo após as mortes de Cazuzza, Freddie Mercury e Renato Russo. A sensação de tristeza e medo era inevitável. Sabemos que muitas vezes a arte imita a vida, ou vice-versa. (2)

[“Philadelphia” came to me soon after the deaths of Cazuzza, Freddie Mercury, and Renato Russo. The feelings of sadness and fear were inevitable. We know that often art mimics life, or vice-versa]. (2)

HIV social stigma was portrayed in movies and the media which resulted in self-stigma as it instilled feelings of despair upon Cezimbra and shaped his perception of HIV from a young age. He was societally molded to believe and uptake at least some of the mainstream view of HIV as his own. Although HIV was a deadly disease in the 1980s that affected all demographics, media portrayal spread terms like “gay plague” and “gay cancer” while propagating fear and stigma towards specifically the LGBTQ communities (Parker “Within”, 262). This resulted in the stigma towards individuals with HIV also being applied to the general LGBTQ community.

Due to his sexuality, Cezimbra grew up constantly being made fun of and being called a *viado* [stag], which is a slur for gay men. He describes his experiences of being in college and being referred to by these terms:

Entre 1996-98 eu era um dos quatro “viadinhos” do colégio. É estranho. Nem eu mesmo até certo ponto tinha sequer beijado outro menino... Para todos, tudo o que eu desejava era errado. Tudo o que eu sentia era sujo. Tudo que eu fazia era motivo de chacota. Eu sempre fui podado. (49)

[Between 1996-98 I was one of the four “little stags” in my highschool. It's weird. I had not even kissed another boy... For everyone, everything I desired was wrong. Everything I felt was dirty. Everything I did was a motive for humiliation. I was always restricted].

Apart from not being allowed to be himself, he suffered constantly due to biases others held.

Stigma involving labeling with homophobic slurs, stereotyping based on a sexual identity and

separation or exclusion while pursuing an education contributed to the self-stigma that Cezimbra developed growing up.

The historical self-stigma that Cezimbra developed around HIV in his teens continued to affect Cezimbra after being diagnosed with HIV at the age of 31. He describes how he started feeling dirty “Eu achava que me abrir poderia me deixar limpo. Muitas vezes eu me sentia sujo no meio das pessoas. Como se eu carregasse um veneno mortal e omitisse” [I believed that opening up would leave me clean. Many times I felt dirty around others. As if I carried a mortal venom and was hiding it]. Additionally, Cezimbra also felt dirty when dating others. Cezimbra went on dates and in one instance they had decided to be intimate. Cezimbra disclosed his HIV+ status and undetectable viral load and they both decided to continue, but shortly after Cezimbra felt prejudice and apprehension from his date as he describes:

Eu senti no beijo dele medo, apreensão, pena e, poderia dizer, até um pouco de nojo - por mais que ele não quisesse sentir isso. Mas acho que tudo se confirmou quando tentei tomar uma iniciativa um pouco mais arriscada e recebi um: “não tem necessidade disso”. Só ajudou para reforçar em mim aquilo de que no fundo eu estava sujo. Me senti imundo... Eu acho que ele tentou, se esforçou para não ter uma atitude preconceituosa. Honestamente, eu preferia ter sido dispensado logo no início. (27)

[I felt fear in his kiss, apprehension, pity, and I could say, even a little bit of repulsion - even though he didn't want to feel that way. But I think everything was confirmed when I tried to take a little more risky initiative and received: “this is not necessary”. It only helped to reinforce for me that deep down I was dirty. I felt disgusting... I think he tried, and made an effort to have an open attitude. Honestly, I would have preferred to be rejected right off.]

Cezimbra's feelings of being dirty and poisonous are related to low self-esteem and associated with stigma. Being constantly stigmatized and rejected by his dates subjected Cezimbra to a constant internalization of bias and reinforced his self-stigma which led to him feeling low self-esteem and contributed to his fear of self-disclosure. Such social stigma originates at the societal level and is nested within the historical contexts and historical portrayal of HIV as a "deadly gay plague" (Parker "Within", 262). Additionally, social stigmas can change over time with changes in society (Fine 165). When society associates an identity or group of people with behaviors that deviate from social norms, fear and discomfort can be created (Corrigan 190). This is particularly applicable to HIV which is associated with homosexual behavior. In Brazil there is prevalent homophobia which is already heavily stigmatized, and the fear and discomfort attributed to homosexuals is often paralleled to that felt towards individuals with HIV. Additionally, if a disease is seen as personally controllable or preventable the victims may be seen to lack personal effort (Manstead 2) and are blamed for their condition and held individually responsible (Corrigan 190). Cezimbra himself recounts his experiences of being asked by friends and family "Mas como isso aconteceu?" (5) [How did this happen?] and "sabe de quem você pegou?" (34) [Do you know who you caught it from?] while being held accountable for not having safe sex and using protection. Social stigma can pose barriers that reduce access to HIV testing and treatment which can have devastating consequences for individuals with HIV (Costa 2536) thus furthering stigmatization.

Being diagnosed with HIV, Cezimbra had to battle his own self-stigma as well as that of his family. Following being diagnosed with HIV, Cezimbra faced his family's and friend's misconceptions and stigma related to HIV which put him in a position where he wanted to hide in privacy and thus delay treatment. Revealing his condition to his family also made him feel

guilt for bringing so much suffering to his family. Besides all the misconceptions, when he told his family about his diagnosis, he also had to almost prove that he had HIV after they insisted on the result being an error.

Me debrucei na mesa do PC e não conseguia organizar meus pensamentos. Nisso, meu ex-cunhado chegou. Assustado, ele me perguntou sobre o que tinha acontecido. Ele jamais tinha me visto daquela forma. Eu nem consegui responder, só dei o exame pra ele. Ele leu e disse: “calma, pode ter dado um erro”. Eu falei: “um erro duas vezes?”

Acontece que quando meu exame deu positivo aqui na minha cidade, meu sangue foi enviado para POA justamente para confirmação, logo eu tinha dois resultados confirmando que meu exame deu reagente para HIV. (5)

[I rested my body on the computer table and couldn't straighten my thoughts out. When my ex-brother-in-law arrived. Frightened, he asked me what had happened. He had never seen me like that. I wasn't even able to respond, so I just handed him my test results. He read and said: “Calm down, there could have been an error”. I said: “an error twice?”

When my exam gave a positive result here in my city, my blood was sent to another lab to confirm the result, I have two tests confirming my reagent status for HIV.]

Having to constantly explain to several family members about his status and explaining to them that there was no error had a significant impact on Cezimbra as he had to re-experience the stress of sharing his test results and “convincing” others that the test results were correct. Overall, this had a significant impact on Cezimbra. He had to process his diagnoses and convince his family that his results were accurate and that he really did have HIV. This eventually led him to want to retreat thus delaying care and putting him at risk of progressing more towards AIDS.

After notifying his family and friends of his status, Cezimbra began getting frequent visits from his family and friends and they began treating him like he was dying which led Cezimbra to question and feel anxious regarding his life expectancy. He describes his experience of getting dropped off at his home and immediately his friend calling him:

Foi só eu pisar os pés fora do carro que meu celular tocou. Era uma amiga muito importante. Nesse momento fiquei sabendo que meus amigos estavam loucos tentando falar comigo. Ela falou comigo chorando: “como você está? Não vai morrer né? (7) [As soon as I stepped out of the car my phone began ringing. It was a very important friend. At this moment I learned that my friends were crazy trying to get in touch with me. She said to me crying: “how are you? You’re not going to die, right??”]

Cezimbra’s family and friends shifted the way they treated him and the way they talked to him. Each time his friends and father visited him they spoke as if they were saying their goodbyes and his friends often called him frantically while crying and asking if he was going to die. His mother did her best to stay strong and to support him, but he knew she too was struggling. All of this brought him anxiety and stress in wondering how long he really had left to live. The misconceptions about how long people infected with HIV really lived with modern care indicates that the misguided belief is likely to be deeply rooted in the historical accounts of the disease. Additionally, most of Cezimbra’s friends and family held this belief regarding the HIV life expectancy and being constantly exposed to it Cezimbra himself started to internalize some of those beliefs:

Muitas dúvidas do passado, do presente (como por exemplo no que isso influenciaria minha vida efetivamente) e do futuro, afinal, na minha cabeça eu poderia morrer em dois

meses. Parece piada, mas quando você recebe uma notícia dessas a primeira coisa que vem na cabeça é que você vai morrer logo. (8)

[Many doubts about the past, about the present (like for example, how this would influence my life immediately) and about the future, since in my mind I could die in two months. It sounds like a joke, but when you receive this kind of news the first thing that crosses your mind is that you will die soon.]

Not having informed himself regarding HIV, Cezimbra internalized much of the misguided beliefs of those around him and as a result began to believe that he would likely die in two months. The social stigma from those around him was internalized by Cezimbra and resulted in distress, hopelessness and lack of self-advocacy.

As Cezimbra progressed through treatment, he began to change his sleeping habits and party less, leading him to withdrawing from friends and relationships. While trying to keep his status a secret, Cezimbra felt pressured by friends to share his condition when they didn't understand why he couldn't party. He outlines one experience where a friend of his would not take no for an answer and kept insisting on him going to his party:

No caminho o meu amigo, dono da festa, me buzinou e parou o carro. “E ai, está mais tranquilo?”, ele disse. Eu respondi que estava tudo numa boa. “Ficarei muito triste se não for na minha festa, não vou perdoar”, mas eu insisti dizendo que não estava em condições no momento, que devido aos meus problemas eu estava tomando remédios que não me deixavam beber, etc. Mas o papo continuava. A insistência da parte dele continuava. E eu na negativa... Eu só pensava: “que raios a pessoa não consegue entender que a outra não está bem”. Então veio a pergunta: “mas o que você tem afinal?”(14)

[On the way my friend, who was having the party, honked and stopped his car. “What’s up, are you ok now?”, he said. I responded that everything was good. “I will be very sad if you don’t go to my party, I will not forgive you”, but I insisted saying that I was not able to at the moment, that given my problems I was taking medications that prevented me from drinking, etc. But the topic continued. He continued to insist. I continued declining... I just thought: “Why the hell can’t someone take the hint that someone else isn’t doing well”. And so, he asked: “but what do you have anyway?”]

Even after sharing his status his friends still didn't understand. Cezimbra felt intensely pressured to be social but at the same time he was battling the symptoms of ART treatment. As he slowly broke apart from certain friends, others stayed connected. Many people wanted to get to know him but he refused, as he was afraid of what people would think and that people wouldn't understand his HIV or they would say something mean about it. Eventually he felt that people stopped seeing him for who he was and started seeing him for what he had which reinforced negative self-perception.

Because of self-stigma, Cezimbra began to avoid social interactions out of fear of what people may say or think of him. He felt vulnerable to the perceptions of those around him. He wanted to seek social support but to do that he would have to overcome the social stigma. Each time he told someone else about being HIV positive he felt a weight taken off his chest. He compared the feeling of telling others about being HIV+ to coming out of the closet about his sexuality. At the same time telling others about his status exposed him to stigma and negative perceptions. Meanwhile, not telling close friends about his HIV+ left him feeling like he wasn't being transparent and honest with them. This is described by Cezimbra:

Eu sou o tipo de pessoa transparente. Não gosto de mentir e esconder minha sorologia, era mentir sobre quem eu era. O vírus estava em mim agora. Eu não sou o HIV, mas ele faz parte de mim. O quanto mais eu levar isso com naturalidade, mais as pessoas vão entender do que se trata. Nesse momento começou a nascer em mim a semente da militância. Nesse momento eu pensei que de repente tudo isso poderia virar uma missão. Não era para amanhã, ou para o próximo mês, mas algum momento. (19)

[I am a transparent kind of person. I don't like to lie and hide my serology, its lying about who I am. The virus was in me now. I am not HIV, but it is now a part of me. The more I naturally accept this, more people will understand me. At this moment the seed of activism began to grow. At this moment I thought that suddenly this could become a mission. It wasn't for tomorrow, or for the next month, but for some future moment.]

Despite having a fear of disclosure due to not knowing how others would react when they heard about his HIV+ status, Cezimbra was able to grow and learn how to cope with his HIV. With this he was able to practice more self-advocacy and grow his interest in advocacy. Cezimbra was able to overcome many of the stigma related obstacles he experienced partly through the extensive support he received from his friends and family.

In Cezimbra's account, social networks provide him with extensive support from the moment of diagnosis to after beginning treatment. Understanding social support that Cezimbra received is crucial for understanding Cezimbra's decision to begin and continue treatment. Social support can be defined as any support that is accessible to an individual via their social ties to others (Heaney 192). Social support played a critical role in Cezimbra learning to cope with HIV and in beginning treatment for HIV. Cezimbra was especially dependent on his mother and siblings support when he was first diagnosed with HIV as they helped to validate him, reassure

him as well as persuading him to get medical help and begin treatment. Simultaneously, his family also brought him comfort and reassurance regarding his diagnoses:

No que eu abri a porta lá estavam todos. Meus irmãos, meu ex-cunhado, minha sobrinha... meus pais. Todos muitos abatidos, todos com o rosto inchado de chorar. Mas meus pais vieram até mim. Eu tinha crises compulsivas de choro e soluço. Eu sabia qual seria a reação deles no fim. O apoio incondicional, as palavras de amor. Nunca duvidei disso. Mas me acabava saber que tinha sido a causa de tanto sofrimento e medo naquele dia. Algo que eu poderia ter evitado. (7)

[When I opened the door, there was everyone. My brothers, my ex-brother-in-law, my niece... my parents. Everyone was sad, all with swollen faces from crying. My parents came to me. I had compulsive crying and hiccup attacks. I knew what their reactions were going to be in the end. Unconditional support, loving words. I never doubted this. But it devastated me to know that I had been the cause of such suffering and fear that day. Something I could have prevented.]

His family was very supportive and although he felt guilty seeing his family suffer, their support made a significant impact on his ability to cope with HIV and in taking the most critical first steps in seeking treatment. His sister said that he was not alone and that she knew other friends who had lived a long time with HIV, thus bringing reassurance to Cezimbra's in regard to his life expectancy. His mom insisted on immediate medical treatment and booked him an appointment with a doctor. This helped him learn more about the condition and understand his situation accurately and get clarity, it also allowed him to begin treatment earlier than he may have otherwise. Beginning treatment early through the support of his mother allowed him to begin accessing information about HIV soon after being diagnosed as he explained:

Então, quando cheguei em casa minha mãe me avisou que tinha marcado uma consulta para mim na UNIMED. Além disso, me sentei no PC e enfrentei longas horas de pesquisa, leitura e estudo sobre o HIV. Descobri coisas que nem imaginava que existiam, como diferença entre HIV e AIDS, o que é CD4, carga viral, Efavirenz, entre outros nomes. (8)

[So, when I arrived at home my mom told me that she had scheduled a consultation for me at UNIMED [private clinic]. Along with that, I sat at the computer and withstood long hours of research, reading and study about HIV. I discovered things that I never imagined existed, like the difference between HIV and AIDS, what CD4 is, viral load, Efavirenz [ART drug brand], along with other names.] (8)

Meeting with a doctor about his condition enabled Cezimbra to learn about treatment options, medical advances in treatment, as well as allowing him to connect to HIV+ social networks that provided him help and support. Additionally, his mother also accompanied him on all consultations with the doctor:

Sexta-feira, depois de trabalhar pela manhã e do almoço, eu tinha minha primeira consulta com o médico da UNIMED. Minha mãe foi comigo. Aliás, tenho que salientar: minha mãe me acompanhou em todas consultas e atendimentos iniciais. Pediu licença do trabalho para poder me dar esse suporte. (9)

Friday, after working during the morning until lunch, I had my first consultation with the doctor at UNIMED. My mother went with me. Besides, I must admit: my mother accompanied me to all consultations and initial appointments. She requested time off work to be able to give me support. (9)

Without his family support, Cezimbra would have likely delayed treatment and possibly have been less confident in seeking self-help resources like HIV+ online support networks and medical help. This is supported by Silva's observations "We observed that with the support of family and friends the HIV sufferer is able to live with the infection with more courage to continue living despite having a chronic disease that requires constant care and attention" (1112). Additionally, having his mother schedule a consultation prompted him to want to prepare with knowledge about HIV related terms which allowed him to become more educated in HIV and empowered him to connect with online support networks.

Despite social support and social stigma both being unique factors that affect Cezimbra's journey with HIV, they are not exclusive from one another, and they can both exist concurrently within the same space. Analyzing how stigma and support can act in the same space can reveal interesting effects that both can collectively have on Cezimbra. In many accounts of social support from his family or friends, Cezimbra also describes stigma and the tense atmosphere. One such example is when family and friends increased social support due to their belief that Cezimbra would die. As a response to Cezimbra's HIV diagnoses, many family members and friends increased their presence in Cezimbra's life and treated him like he was dying. The increase in their presence originated from a misconception of the mortality of HIV which created a tense and anxious atmosphere for Cezimbra. He outlines how his fears kept growing as he lived during this anxious phase of learning to live with HIV:

Muitos medos também. Medo de ter que parar de trabalhar, logo em meu momento de ascensão profissional. Medo de não ver minha sobrinha que mal tinha completado um ano crescer. Medo de perder emprego, amigos, respeito de

todos. Medo que todo mundo soubesse. Que eu virasse o “aidético” da vez.

Medos, medos e medos. (8)

[Many fears too. The fear of having to stop working, right during my career growth. Fear of not seeing my niece that had just completed her first year. Fear of losing my job, friends, respect from others. Fear that everyone would know. That I would turn the “aidetic” at once. Fears, fears, and fears.] (8)

The support from his family and misconceptions from his family put Cezimbra in a concurrent space where the belief that HIV was a death sentence was regularly spoon-fed to him by well-intentioned family and friends. The constant exposure to the topic of death led Cezimbra to begin fearing several aspects of his life. From his job to his niece, he began to think about everything he was leaving behind and began anxiously anticipating his death. Along with this he internalized the stigma regarding HIV. Although the combination of self-stigma and the stigma from his family led him to potentially be less hopeful and socially withdraw. His family also was critical in providing the support that he needed. As they increased their presence they also demonstrated care and love. By his mom insisting on immediate medical treatment and booking him an appointment, the social support in this situation both helped Cezimbra start treatment while also subjecting him to greater internalized self-stigma affecting his ability to cope with HIV.

Beginning treatment posed a great challenge that increased his dependence on his social network. During his treatment, Cezimbra displayed the strong symptoms from the ART drugs which left him unable to stand or talk and caused sickness and headaches during the day. This left him dependent on his family and friends to help care for him and watch over him. Having his family around offered a great benefit in that it offered him the support and help needed to

continue treatment but at the same time increased the feeling he felt of being a burden and bringing suffering to his family. But even when Cezimbra wanted to give up and stop treatment, it was his family support that reminded him of why he was getting treated and brought him comfort:

Nessa época por um curto período eu pensei em desistir. Um dia eu estava no meu quarto com minha irmã e tive uma crise. “Eu não aguento mais... Não quero mais isso”, falei chorando. “Ninguém merece isso, não consigo sair da cama”. Minha irmã me manteve calmo. Me fez lembrar que mais um curto tempo e eu provavelmente estaria melhor. (22)

[During this time for a short period I considered giving up. One day I was in my room with my sister, and I had a crisis. “I can’t handle this anymore... I don’t want this anymore”, I said crying. “No one deserves this, I’m incapable of leaving bed”. My sister kept me calm. She helped me remember that another short while and I would probably be feeling better.] (22)

Cezimbra’s sister is a great example of how social support encouraged and helped Cezimbra continue his HIV treatment. Overall, it can be noted that stigma originating from historically based conditions and victim blaming contributed largely to the stress and fears relating to being HIV positive, but his social network supported him during the most challenging times leading up to his treatment and during his treatment. Understanding the impacts arising from social support and stigma can help to clarify factors that affect medical approaches to treating HIV. The experiences of Cezimbra outlining guilt, shame, and fear of disclosure contrast with the main medical discourse where HIV is treatable. This showcases how in Cezimbra’s societal experiences, ignorance around HIV prevailed and public discourse regarding HIV was one of risk and death which was also propelled through the silence around HIV. Meanwhile the

dominant medical discourse is the promise of being able to live a normal life through treatment (Walker 99). This highlights, as Persson argues, that “society's knowledge about HIV lags behind extraordinary strides in biomedicine” (210). Cezimbra’s account of his experience reveals how society's outdated knowledge can interfere with how people with HIV are supported and can have potentially catastrophic consequences when it comes to initiating treatment quickly. This is particularly evident where Cezimbra, after being diagnosed, cried and isolated himself when his family believed he would die soon. This illustrates how stigma and social support in a concurrent space can be discussed in regard to the effectiveness of HIV treatments for individuals diagnosed with HIV. Such discussions reveal social factors affecting HIV treatment that are absent from medical discourses regarding HIV treatments. Considering such aspects in HIV treatment would allow for a more effective treatment and delivery of ART HIV treatments. Additionally, Cezimbra’s account suggests that family members of those who contract HIV or another disease, should educate themselves in order to best provide support. Otherwise, it is possible that the support they provide acts as a vector for any stigma they hold similar to how Cezimbra’s family cultured the misguided belief that Cezimbra would die within two months. Although Cezimbra suffered from the strain of the concurrent space, by learning that HIV is a part of him but does not define him, he learned to manage and cope with stigma and the fear of disclosure. This is especially evident where Cezimbra describes the seed of militancy as he learns to cope with HIV himself and develops the desire to advocate and support others.

As we see in Cezimbras account of his journey with HIV, the effectiveness of a medical treatment extends beyond the doctor's office. Whether Cezimbra had become aware of his treatment options, decided to engage in the treatment and whether to continue the treatment was all dependent on society and his mother, not only the doctor (Olatunji 112). In Cezimbra’s case,

social stigma, and self-stigma was the reason he decided to withdraw and potentially delay treatment, but his mother was the reason he began treatment immediately and his sister supported him during treatment. This experience is not specific to Cezimbra; stigma is a barrier to HIV care and the fear of HIV disclosure can potentially be deadly (Madiba 962). Additionally, stigma and support often coexist. Within a concurrent space, Cezimbra often felt pressured and anxious as social support often acted as a vector for the social stigma present in society. Although overcoming any kind of disease-related stigma can be challenging, Cezimbra's account highlights the importance of providing support rooted in scientific accuracy when it comes to diseases in order to avoid further propagating stigma during sensitive situations.

Health Care approaches often focus on treatment and caring for the patient but rarely include the patient's family (Maizes 279). Due to societal knowledge regarding HIV being behind that of modern medicine it is important to consider the challenges this can pose for HIV patients. In Cezimbra's case he had to constantly battle the internalized stigmas that his family held around HIV as his family believed that HIV was a death sentence. This led to a lot of stigmatization of Cezimbra. At the same time, Cezimbra's HIV treatment was heavily dependent on his family. If Cezimbra's family had either been educated about HIV prior to Cezimbra's diagnoses or been educated upon his diagnoses, there would have been less stigma accompanying his social support thus allowing for a potentially more effective HIV treatment.

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