STANDING UP SPEAKING OUT

WOMEN AND HIV IN THE MIDDLE EAST AND NORTH AFRICA



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MENA-ROSA:
Empowering Women Living with HIV

The voices in this report belong to a remarkable group of women. They are the founding members of MENA-Rosa, the first regional association dedicated to women touched by HIV in the Middle East and North Africa. Launched in 2010, MENA-Rosa's mandate is ambitious, as are its members, in their own words:

"MENA-Rosa is a group of women who will work for the rights of women working for dignity and love. The name of the network originates from MENA [Middle East and North Africa] for the region, and Rosa as the first black woman on a bus in the US who refused to give up her seat to a white man, starting the civil rights [movement] for black Americans. Rosa is also a feminine symbol. Our friend Zouheira started this process in Algeria seven years ago, as the first woman to raise her voice. She demonstrated to us, by her courageous actions, that we are able to have a group and to raise our voices as well. Our objectives are numerous, as we find that the particular needs of women are, in fact, different from men's, ie, sexual and reproductive health, children and families. The outcome would be to impact the health of the woman and her family in the MENA region."

Through face-to-face meetings, and long-distance networking, MENA-Rosa offers women living with HIV (WLHIV) a much-needed opportunity to talk about their many trials, and occasional triumphs, in dealing with HIV, from medical matters to family affairs. But for change to take root in their personal lives, the members of MENA-Rosa are looking to fix the big picture, raising awareness among key decision makers of the many needs of WLHIV, and mobilizing money to reach their goals. To this end, in 2011 MENA-Rosa solicited the views of 140 WLHIV in 10 countries across MENA (Algeria, Djibouti, Egypt, Iran, Jordan, Lebanon, Morocco, Sudan, Tunisia and Yemen); their voices, highlighted in this report, offer unique insight into the experiences, and aspirations, of WLHIV in the Middle East and North Africa.

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EXECUTIVE SUMMARY

Women are on the frontlines of HIV across the Middle East and North Africa (MENA). Of the estimated 470,000 [340,000 – 540,000] people living with HIV in MENA, approximately 40% are women. Their numbers are set to grow: MENA is one of only two regions of the world where new HIV infections, and AIDS-related deaths, continue to rise. The majority of countries in MENA are witnessing concentrated epidemics, among most-at-risk-populations, and in most countries, sex is the main route of transmission. This means that women are touched both directly—as injecting drug users or sex workers—and indirectly—as the sexual partners of clients, or injecting drug users, or men who also have sex with men. Wives are hit particularly hard: in a number of countries, the majority of women living with HIV have been infected by their husbands.

A complex set of social, economic and cultural factors make women across MENA especially vulnerable to HIV. While female literacy and education has advanced over the past decade, this has not translated into a significantly greater presence in the workplace. Female unemployment rates are at least double those of men across the region, and even higher among female youth. Economic insecurity increases women's vulnerability to HIV. Condom use is rare, within and outside of marriage; significant proportions of women have been shown, in studies across the region, to experience gender-based violence, both at home and in public places.

But it's not just economics that it is putting women at risk. Cultural norms that favour men, mistakenly cloaked in religion and reflected in national law in many countries, increase women's vulnerability. This is particularly true when it comes to questions of sexuality, in which women are held to double standards of virginity and sexual monogamy. Young women in particular have fewer opportunities to seek out information on sexual and reproductive health, a situation reflected in significantly lower levels of knowledge of HIV/AIDS than their male counterparts. Social constraints—particularly on unmarried women—make it difficult to access sexual and reproductive health services, including HIV prevention and testing.

Women living with HIV face many personal, social and financial challenges. Stigma and discrimination is even fiercer against women living with HIV than men, given societal expectations of female behaviour and a popular association between infection and "illicit" practices, such as sex outside of marriage or drug use. Those women who do work can find themselves swiftly out of a job should their HIV-status be disclosed. Family members and neighbours can be equally dismissive, which makes women reluctant to reveal their situation to others. Even more vulnerable are the millions of female migrants and refugees across MENA, who often lack even the meagre support offered to local women, and are further discouraged for coming

forward for testing or treatment because of unjust laws in a number of host countries which either prevent entry or force the departure of those testing positive for HIV.

Medical care is already a problem for people living with HIV in most countries of the region, with scarcely 10% of those eligible for treatment with anti-retroviral therapy (ARVs) receiving the medicine they need. Stigma and discrimination is pronounced among health practitioners and this is particularly difficult for women during pregnancy and delivery. These problems extend to their children as well, especially those who are themselves living with HIV; paediatric AIDS care is underdeveloped in MENA, unlike societal prejudice, which is flourishing.

Law, religion and media are institutions that could help women to overcome many of these hurdles; in practice, however, they are still of little assistance to those in need. Civil society is, however, making a difference, helping women living with HIV to deal with their everyday challenges, as well as addressing the broader structural problems that leave them vulnerable to infection. Groups like MENA-Rosa, the first association of women living with HIV across the Middle East and North Africa, are raising their voices and advocating for reform. Among the changes women living with HIV recommend:

- Improved access to quality education and employment for girls and women
- Financial and social support to women as caregivers
- Guaranteed access to the best available care for HIV, including sustained anti-retroviral therapy, treatment for opportunistic infections and viral monitoring, all free at the point of delivery
- Special training of doctors, nurses and other medical personnel to reduce stigma and discrimination towards people living with HIV
- Better access to sexual and reproductive health information and services, including HIV prevention and testing, for both married and single women
- Policies, projects and enabling legislation that specifically address the needs of women at higher risk of HIV infection, including female sex workers and women who inject drugs
- Further engagement of religious leaders to reduce community stigma and discrimination
- Concerted efforts by government and civil society to raise awareness and reduce the incidence of gender-based violence in the public and private spheres, with an emphasis on projects which educate and engage boys and men
- Changes in legislation and law enforcement to help women realize the same political, economic and social rights as men

The shifting political order in the Middle East and North Africa presents new challenges to, and new opportunities for, a better life for all citizens. For women living with HIV, the changes they want to see cannot come soon enough.



1. INTRODUCTION

> *I would rather be shot than live with this disease.* ***People do not know AIDS; for them, it means illegitimate sexual relations.***

Woman living with HIV, **Sudan**

> *I live a normal life; this disease is like other diseases.* ***This disease is from God.***

Woman living with HIV, **Lebanon**

Two different voices, two different views. These women are among the estimated 470,000 [340,000 – 540,000] people living with HIV in the Middle East and North Africa (MENA).[1] From a slow start, HIV is gaining ground: MENA is one of only two regions in the world where the numbers of new infections, and deaths from AIDS-related causes, is still rising. With the exception of three countries—Djibouti, Somalia and South Sudan, where the bulk of HIV transmission is taking place among the general population —HIV in MENA is concentrated in certain "key" populations, among them people who inject drugs, men-who-have-sex-with-men and sex workers.

If you ask people in MENA to put a face to HIV, it is, invariably, a man's. And no wonder: with a few notable exceptions, men account for more than three-quarters of known infections in most countries in the region. But these are the officially reported cases: behind them lie hundreds of thousands of undetected or unregistered infections. Among these

are the region's most vulnerable people—those who, because of personal circumstances or sociocultural constraints, do not come forth for testing or treatment, conditions which leave them open to infection in the first place. This hidden epidemic has distinctly female features: according to UNAIDS estimates, women account for more than 40% of adults thought to be living with HIV in the region.[2]

No man is an island, at least where HIV is concerned. In much of MENA, unprotected heterosexual intercourse is the main documented route of transmission—and that puts women at additional risk of HIV. In Morocco and Saudi Arabia, for example, more than 70% of women known to be living with HIV acquired their infection from their husbands, a trend observed across the region.[3] But it's not just wives who are vulnerable: women who themselves engage in risk-related behaviour, including sex work and injecting drug use, without adequate protection, are wide open to infection. Many countries across the region are already witnessing a shift towards more HIV infections among women: in Tunisia, for example, the proportion of infected women to men has almost doubled since the mid-1980s and, in Iran, infections are rising faster among women than men.[4] Neighbours that have already moved to a generalized epidemic point the way: in South Sudan, parts of Somalia and Djibouti, for example, women account for more than half of reported cases of HIV.

While still at an early stage of the epidemic, the Middle East and North Africa has an opportunity that millions elsewhere in the world are literally dying for—the prospect of stopping HIV in its tracks. But to do so, MENA must confront HIV at the heart of its society—in its mothers and daughters, wives and sisters—the women of its world. And to do that means tackling not only HIV, but also the myriad political, economic, social, cultural and religious conditions that can help or hinder women's chances. At a time of political transition across the region, this will be one of the emerging order's toughest tests.





2. A WOMAN'S WORLD

Amal has been living with HIV for more than two years. She resides in Beirut, or at least she used to: the day she shared her story, Amal was sitting among packing crates and suitcases, getting ready to move down south. "We can't pay the rent on our home in Beirut anymore," she said sadly. HIV is both the cause of her family's departure and one of the main reasons for their desire to remain.

Amal's husband was unaware that he was infected with HIV, until fatigue and spiking temperatures sent him to the doctor, and an eventual diagnosis. "He spoke to his supervisor at work about his situation," Amal said. "They asked him to resign." The family is now struggling to make ends meet, since Amal's condition means that she can no longer work either. "Our financial level is zero," she said, hence their move away from the costly capital.

But money is not their only problem. Amal isn't dealing with just HIV, having been infected through her husband; she also has bone and breast cancer, a persistent worry for her as she contemplates the future for her son and daughter, both under age five. "My wish in life is that my children stay well," she wept. Added to her burdens is secrecy; while her husband's family is aware of his condition, she has told her relatives only about her cancer. "I am afraid that my family knows my secret; because their mentality is too traditional, I do not say it [that I have HIV] in front of them." But financial concerns mean that she and her husband are moving back to them. "This will take us away from the doctors and treatment," she said. 'But there is nothing to be done."

Amal is not a "typical" woman living with HIV. There is no such thing. As the women of MENA-Rosa attest, their lives are vastly different, across distinctions of wealth, education and age. They are separated by geography—not just borders between countries, but borders within them, from city centres to rural outposts. Some are migrants, some are sex workers, some are married with children, and some are single. But for all their differences, there are key features that bind them together, not just as women living with HIV, but as women full stop—economic, social, cultural factors that profoundly influence their vulnerability to, and their ability to live with, HIV.

Facts of life: education, information and knowledge of HIV/AIDS

In much of MENA, great strides have been made in girls' education. Female and male youth literacy rates are on a par in most countries of the region, although some states, among them Yemen, are still struggling to bring these into line since poverty, early marriage, conflict and other factors conspire to keep girls away from school.[1] Nonetheless, much of MENA is succeeding in overcoming these obstacles, with the result that the gender gap in primary and secondary education is also on its way to closing in most countries.[2] As for higher education, in some parts of the region—notably a number of Gulf Cooperation States—female university enrolment vastly exceeds that of men.

Although some young women are still missing out on school, the problem for the majority of them is that the education they, like their male counterparts, can now access is simply not up to the task of preparing them for work in a modern, globalized and privatized economy. Survey after survey shows the serious deficits in curricula, facilities and teaching across much of the region, deficiencies that challenge both men and women, and will be one of the biggest challenges facing the emerging democratic systems.[3]

> *I do not know how I got infected with AIDS. I only know I was infected in the summer.*
> ***I knew that I might be infected by myself because I was reading books and surfing on the Internet.***
>
> Woman living with HIV, **Algeria**

Nor are such educational systems adequately preparing young men, and women, for other aspects of life. Sexual and reproductive health education is scanty in state schools across the region, at best reduced to a few technical points in biology class, from which many girls find themselves excused, especially if their teacher is a man. While there are a few welcome attempts to introduce sexuality and reproductive health curricula into school systems, most notably in Lebanon, school remains the last place most young people learn about such matters—young women turning to their mothers, and young men to their friends. For more educated and affluent youth—particularly young men—the Internet is a prime source of information, both accurate and fantastic.[4]

The upshot is an extremely weak understanding of HIV among young people across the region, although there are some exceptions, among them Morocco and Lebanon, where surveys show a firmer understanding of HIV than elsewhere. In a standard measure of knowledge of HIV among youth—correct answers to five questions about routes transmission—less than 10% of those aged 15-24 in Yemen, Oman, Algeria, Sudan, Tunisia and Egypt made the grade.[5] In these, and other countries where youth have a greater knowledge of HIV, there is a persistent gender gap, young women lagging a few percentage points behind their male peers in correct responses.

Greater knowledge, however, does not necessarily translate into more informed action. In a recent survey of almost 1,600 public high school students in Lebanon, more than 80% correctly answered a number of key questions about routes of transmission (through unprotected sex or sharing of needles, for example), among the highest scores in the region. And yet, more than half thought people living with HIV should be kept in isolation and almost three-quarters thought infection is a "consequence of one's irresponsible acts".

More than three-fifths of the young women surveyed refused to consider an HIV test, and condom use was hit-and-miss among the substantial numbers of young men admitting to an "intimate relationship". [6]

Elsewhere in the region, knowledge of HIV and AIDS is even more haphazard, particularly among older, poorer, less educated, more geographically isolated women. In a survey of ever-married women aged 15-49 in Egypt, for example, at best 15% of the wealthiest quintile had a "comprehensive knowledge" of HIV and AIDS, a standing that 2% or less of their poorest, least educated counterparts achieved. By contrast, more than a quarter of the wealthiest and most educated men could claim such knowledge, a gender gap that was even more pronounced among younger cohorts.[7]

The challenge in getting accurate information about sexual and reproductive health in general, and AIDS in particular, to women—especially young women—is about more than reading and writing. Taboos around sexuality—especially female sexuality—and the emphasis on female virginity discourage free and frank exchange of information and ideas on such matters for women, as well as discouraging their access to youth and women-friendly clinics which could provide such vital information and services.

> *In 2000, my husband was admitted to several hospitals because of severe weight loss and signs of ill-health; none of them could come up with a diagnosis.*
>
> ***After a long battery of tests, he was informed that he had AIDS and was summarily discharged. He was told, "There is nothing we can do for you here." When he told me about this, I did not have a clue about this illness. It was, in fact, the first time I had even heard the word "AIDS".***

Woman living with HIV, **Iran**

Woman's work: economics

Gains in women's education across MENA have not translated into a corresponding presence in the workplace. On average, women make up about a third of the workforce in the region, one of the lowest rates of female labour participation in the world. Not only are there fewer women in the world of work, but those who do find a place are earning less than their male counterparts, despite labour laws in most MENA countries vouchsafing gender equality in wages.[8]

> *I used to sell and buy (wholesale), but when I was married my husband no longer let me do my job.*
> ***My income has fallen from what it was in the beginning. I have cooking skills, but I am not able to work.***
>
> Woman living with HIV, **Morocco**

> *I have no monthly income. I have four orphans. I have no legacy, neither from my first husband nor my second.*
> ***Only the charity associations help me each two to three months.***
>
> Woman living with HIV, **Yemen**

Double-digit unemployment is a persistent problem in much of MENA, with rates significantly higher among youth, and particularly young women. Against this backdrop, there is a pervasive bias towards male employment, bolstered by Islamic interpretations of gender roles, with surveys showing that when work is scarce, both women and men believe it is men who should get the jobs.[9] Back at home, men also have considerably more sway in financial decision-making than women.

Women can also find their economic options constrained by social norms that, for example, restrict their mobility. Their rights of inheritance are officially circumscribed by law in most countries of the region that, in accordance with shari`a, grant women half the legacy of their male relatives. What property or resources women do possess are often within the control of male relatives in any case, through choice or social pressure, which further limits women's economic latitude.[10]

Evidence from around the world shows that economic dependence increases women's vulnerability to HIV, by reducing their power to negotiate safe sex or to leave violent relationships associated with heightened HIV risk.[11] But even more risky than being than being dependent on men is not having them at all. Cut off from a male financial lifeline, through death or divorce, female-headed households can find themselves in dire straits.

> *I have no money, no people; I am divorced and I have a son. I do not work, I live with my sister; she helps me, she works and I take care of the children.*
> ***I live on charity. I even started to beg: this Ramadan I went to the mosque to beg for clothes for my son. I am even asking for money for transportation in order to come to the hospital.***
>
> Woman living with HIV, **Morocco**

In our country, we fled from hunger and came to Yemen. We have no salary or anything. I cannot be employed as I have only the school degree, so I am not able to work. My family sends to me what they can to pay the house rent only.

For nutrition, I cannot care about it. I also do not care about the virus or anything. All that I care about is to satisfy my stomach's hunger and that's it.

I eat anything, it is not important to have vitamins or nutrition or anything.

Woman living with HIV, **Yemen**

> *I am a tailor. I am afraid to hurt myself and transmit the infection to others. I cannot work without telling the owner of the factory.*
> ***I live with my family. I do not have the right to ask for anything, except for eating and drinking.***

Woman living with HIV, **Algeria**

> ***Before knowing that I was sick, honestly I was with a very good and generous income. But when I was infected, work refused that I continue there.***
> *I lost my job because that work was a reputable work that demanded medical tests, and I was not able to bring a "disease free certificate". Now I have a big difference in my life and income than before.*

Woman living with HIV, **Jordan**

HIV further jeopardizes the economic security of women and their families. When men and women are too sick to work, households can face severe consequences, as the experiences of MENA-Rosa's members clearly demonstrate. HIV is a double whammy: not only is income reduced, but illness brings with it a host of other medical expenses—tests, medications and other procedures—which the state often fails to provide in practice, despite all its fine words on paper. Basic needs, such as a healthy diet, are all the more important for people living with HIV struggling to maintain their immunity, yet the attendant poverty that faces many women living with HIV puts these necessities even further out of reach. Moreover, women living with HIV are often doing double duty—trying to look after themselves, as well as bearing primary responsibility for caring for infected husbands and children.

Even when men and women living with HIV are able to work, employment is hard to get, or to keep, because of discrimination, despite labour laws that, in theory, should protect them from such treatment.[12] In one study of HIV in the Egyptian workplace, more than half of participants said they would not "feel comfortable" with a colleague known to have HIV; indeed, barely a third thought that people living with HIV should be allowed to work at all.[13] With awareness training, however, acceptance of people living with HIV in the workplace in this particular study almost doubled.

Unfortunately, such educational programmes are still rare in MENA's corporate sector. No wonder workers often keep their infection a secret from employers and colleagues, which makes explaining absences due to illness, and claiming compensation, all the more difficult. Given the obstacles women already face in getting, and staying, in the workplace, the additional challenges of living with HIV are daunting. Harassment and peer pressure often force women out of work when their infection somehow comes to light.

> *I work as a street vendor and move between departments [in a company]. When it is lunch time, I enter the cafeteria. I do not know how they knew that I was sick. They gave food to a lady to eat, but refused to give me my meal and kicked me out.*
> ***They said rude and ugly words, they insulted my honour, they called me horrible names and assaulted me. I went to the director and complained to him. I also complained to the NGO and asked for my right because I was deeply humiliated.***

Woman living with HIV, **Yemen**

Credit where it's due

With soaring unemployment across the Middle East and North Africa, making a living isn't easy, all the more so if you're a woman. While opportunities are sorely lacking, for many members of MENA-Rosa, there's no shortage of abilities or ambition.

Wijdan is a 32 year old in Khartoum who's been living with HIV for six years. Times are tough: when her husband died, not only did she and her children lose his income, but they were unable to claim further compensation from his employer because her husband had missed too many days of work, absences whose real cause - HIV - he had been too fearful to disclose. When her neighbours discovered that she had HIV, Wijdan and her children had to move to a new apartment, and now making the rent is a struggle.

Her family is living on charity, but Wijdan doesn't want hand-outs. "I have many skills such as baking, doing make up, doing henna beauty treatments. I can also work as a sales person on commission, selling clothes from house to house," she said proudly. But there's a hitch. "I cannot take any advantage of these skills due to the lack of financial capital," she explained. "Any money I can get, I have to spend on rent, and the children's needs and groceries."

Access to credit is one of the key problems facing entrepreneurs across the Arab region. With the exception of Saudi Arabia, none of the countries in the region rank in the global top 50 in terms of access to credit, most falling near the bottom of the international league tables.[14] This credit crunch hits men and women entrepreneurs equally hard.[15] The problem is not one of sex, but of size: small businesses across the region are struggling. Microfinance in MENA lags behind many other parts of the world, reaching only half the proportion of the working population as in South Asia or Latin America, with barely 2.5 million active borrowers, according to some estimates; in Egypt alone, 2 million micro to small enterprises have no financing facilities whatsoever.[16]

Microfinance is an emerging tool in the global fight against HIV. While credit is key - loans from around USD 100-1,000 to those lacking the collateral for traditional lending - microfinance is about more than just money. By providing business training and assistance, as well health and other educational programmes, microfinance has the potential to both mitigate the impact of HIV on households already living with the virus and to reduce the risk of infection in the first place.[17]

One group putting this into practice is El Hayet, in Algeria. Founded in 1998, its former president, Zouheira, is an inspiration to the members of MENA-Rosa, as the first woman to publicly disclose her positive status. With women now making up more than half of reported HIV cases in Algeria, El Hayet has them firmly in their sights. "Women are the pillar of society, they do not support themselves only, but they also provide care for everyone around them, starting with their families and [children]. Women should be productive and run their own lives," says Nawel, the organization's current president. "HIV is not an obstacle."[18]

To this end, El Hayet has introduced a microfinance programme, reaching 150 women living with HIV in Tamanrasset, a remote and impoverished region in the south of the country. In conjunction with the national agency in charge of microcredit, the initiative provides loans of 40,000-120,000 Algerian Dinars (roughly USD 500-1,500). Beneficiaries are primed at a training centre that provides a six-month course in dressmaking, handicrafts, hairdressing and other remunerative activities from specialized vocational trainers. Graduates receive a diploma attesting to their skills; HIV-related knowledge and information is also provided, thanks to a local hospital. Graduates also get help from the national agency in how to set up and run a business in line with market needs, along with advice in how to promote their goods and skills. So far more than 20 women have taken loans, a small but welcome start.

Raised in anger: violence against women

For women around the world, the links between violence and vulnerability to HIV are clear.[19] Violence against women is both a cause, and a consequence of, infection. It can prevent them from accessing HIV-related information; from being tested or disclosing their HIV status; from receiving treatment and counselling; and it disempowers them from protecting themselves, in particular from negotiating condom use with their sexual partners. There is also a growing body of evidence that sexual violence in childhood is linked to risky practices as an adult.[20]

Fear of further violence—as well as the consequences of divorce, including social stigma and loss of child custody—makes it more difficult for women to walk away from relationships that pose a risk to their health. Such is the intimate connection between violence towards women and HIV that the "proportion of ever-married or partnered women aged 15-49 who experienced physical or sexual violence from a male intimate partner in the past 12 months" is a standard indicator in country reporting in Global AIDS Response (GAR) progress reports.

Gender-based violence runs wide and deep across MENA, as a growing number of national surveys demonstrate.[21] In Tunisia, for example, a recent study of almost 4,000 women from across the country aged 18-64 found that almost a third had experienced some form of violence in the past year, including almost a quarter of the most educated cohort.[22] Almost half of these women had suffered psychological abuse, with just under a quarter reporting either physical or sexual violence. "Intimate partners"—husbands or boyfriends—were the main perpetrators of psychological or sexual abuse, but other family members were the main culprits in physical violence. Women with any experience of marriage—wives, divorcées or widows—were more likely to be victims of abuse than their single peers. More than half the women said the violence had affected their daily lives, forcing around two-fifths to leave the marital home.

Such statistics cannot convey the suffering those on the receiving end of such violence experience. Violence at the hands of men—be they fathers or brothers or husbands or boyfriends or employers or clients—is a daily challenge for the members of MENA-Rosa, a personal history which starts for many at an early age and continues throughout adult life. "Life back at the paternal home was tough, a real struggle. [My father] treated me like a prisoner, frequently locking me up in my room. I ran away from home several times," said one young woman living with HIV in Iran. "The police caught up with me as I was about to commit suicide by throwing myself under a train, and turned me over to my father. My circumstances were less tolerable even than before. I finally plucked up the courage one day and, saying farewell to my mother, I left home for Tehran."

Although the majority of countries in MENA are signatories to the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and other international human rights agreements that protect against gender-based violence, few have legislation that specifically and explicitly criminalizes violence against women, particularly intimate-partner abuse or sexual harassment. Marital rape is a particularly sore point, as it has no standing in law in many states in MENA since sexual obedience on the part of wives is considered part-and-parcel of marriage according to conventional interpretations of shari`a.

My husband forced me to have sex, raped me many times. ***I got sick, and he confessed that he is infected with the virus and that he infected me on purpose.***

Woman living with HIV, **Egypt**

Even where such laws exist on paper, enforcing them in practice is difficult. Law enforcement personnel—lawyers, police officers and judges—often dismiss such cases out of hand or rule in favour of men, saying it is their right to "discipline" the women in their charge, a right enshrined, at least implicitly, in law in a number of countries in the region. The extreme example of this state of affairs is the so-called "honour crime", in which violent assault—even killing—of family members, usually women whose behaviour is perceived to have tarnished the honour of their family, and in particular its male members, is punished with significantly reduced sentences, as male assailants are seen by the courts, if not the law on the books, as somehow justified in their actions.

There are welcome attempts across MENA, by governments and civil society, to help women on the receiving end of gender-based violence, with support groups, hotlines, shelters and other assistance. The initiatives are still small-scale, and many women—particularly the poorest, least educated and those in rural and more isolated areas—are either not yet aware of, or do not have access to, such services. Many are fearful of adverse reaction, by their families, communities or authorities, of admitting to abuse, thereby exacerbating an already difficult situation. This is particularly true in the case of sexual violence, from harassment to rape, where shame and the risk to family reputation, among other considerations, conspire to keep women from coming forward. This silence undermines their chances of treatment for sexual assault, including HIV testing, prophylaxis or treatment, in the rare circumstances that such specialized facilities are available. In extreme cases, families have been known to force female victims of rape to marry their assailants, a further act of violence against women, as the recent self-immolation of a young woman in Morocco forced into such a situation tragically demonstrates.[23]

But by far the biggest obstacle to combatting violence against women is the attitudes towards such abuse among men, and women themselves. In the Tunisian national survey, for example, more than 40% of abused women said they had never spoken to anyone about their experience, the majority because violence is such an ordinary occurrence that they felt it wasn't worth discussing. Elsewhere in the region, study after study shows many women, and men, accept violence against women as a fact of life, even justifiable in cases of perceived "disobedience" or sexual transgression. Changing such attitudes is the work of more than just a few brave NGOs, or well-intentioned government initiatives. It will take a wholesale cultural shift in gender norms, so that girls and women are no longer raised to see violence as their lot in life, and boys and men come to learn that violence against women is a symptom of weakness, not a sign of strength.

Below the belt

Female genital mutilation (FGM) is a fact of life for millions of women living in the MENA region. Its form, and frequency, varies according to location. In Egypt, for example, more than 90% of ever-married women aged 15-49 have been circumcised, mainly through Type I and Type II, which involve partial or complete removal of the hood of the clitoris, the clitoris itself, as well as the labia minora and often labia majora. In Sudan, where just under 90% of women aged 15-49 are circumcised, Type III FGM, also known as infibulation, in which the vaginal opening is sewn shut, often along with removal of the clitoris, prevails. Various forms of FGM are also practiced in Yemen, Djibouti, Somalia, Oman, Iraqi Kurdistan and in other pockets across the Middle East. According to UNICEF, an estimated 28 million women aged 15-49 in the region have undergone some form of circumcision.[24]

FGM is associated with a wide range of risks to the health and wellbeing of girls and women.[25] It is commonly included in a range of "harmful traditional practices", among them widow inheritance and "sexual cleansing", which increase women's vulnerability to HIV.[26] A number of reasons have been posited as to why FGM might raise the risk of infection, among them the use of non-sterile equipment, bringing girls into contact with infected blood; the risk of serious haemorrhage necessitating transfusions, with potentially contaminated blood; injuries and complications during sexual intercourse in the case of Type III FGM, raising the risk of infection.[27]

There is, however, little evidence, as yet, to confirm this association. One of the few studies to look at the extent to which FGM might increase the risk of acquiring sexually-transmitted infections, among women with Type I-III FGM in Khartoum, for example, found no connection between the procedure and the presence of sexually transmitted infections.[28] Evidence from Kenya, where a number of studies have been conducted, is mixed. One study of FGM, in young female virgins, found that circumcised women were substantially more likely to be HIV-infected—possibly through contaminated instruments—than their uncircumcised peers.[29] Another piece of research, based on Kenya's 2003 Demographic and Health Survey, however, found no direct association between HIV and FGM; it did, however, propose an indirect association in that circumcised women have older partners, an earlier sexual debut and other risk factors that are directly associated with HIV.[30]

Direct transmission of HIV via FGM is, in all likelihood, less of a risk in settings where there is a low general prevalence of HIV and the procedure has become "medicalized", as in Egypt, for example, where almost three-quarters of girls under-18 are circumcised by physicians.[31] Indirectly, though, the factors that perpetuate FGM also perpetuate women's economic and socio-cultural vulnerability, which increases their chances of HIV infection. And so, while the link between FGM and HIV has yet to be proven, the fact that FGM rates are declining in younger generations is good news for the fight against HIV as well.

Men on top: social structures disempowering women

The last few decades have seen tremendous advances in women's rights across MENA. Early marriage, for example, once the norm is now a minority practice in many countries in the region; where it is still prevalent—in Yemen, for example—efforts in law and on the ground in communities are helping to reduce the practice, and to correct the often religiously justified support for it.[32] This is encouraging for the fight against HIV, since early marriage is a known contributor to women's vulnerability to infection.

Elsewhere, there have been remarkable strides in law—at least on paper in many countries. These changes allow women to initiate no-fault divorce, known as khul`; to register their children's births under the own name, and to pass their nationality to them; to travel without the need for a guardian's permission; to be consulted, and provide consent before their husbands take other, concurrent wives. These and other legal amendments, which give women more personal, social and economic power, are helpful in reducing the myriad vulnerabilities to HIV.

But laws on paper do little when attitudes in practice make them hard to enforce. Patriarchy remains a powerful force at all levels of life in MENA—from the political to the personal. Divorce may be legal for women, but it is far from socially acceptable in many quarters; women are as educated as men, but it is harder for them to find jobs; where they do find jobs and earn a living wage, they are unable to exercise the independence and rights—including sexual rights—enjoyed by their male peers, for fear of reputation—their own and by extension that of their family. Too often, these socio-cultural constraints are justified on religious grounds, when in reality, religion is a cover for such social norms, rather than a source of them.

Women across MENA are hemmed in by restrictions—political, economic, social and cultural—that limit their scope and indirectly increase their vulnerability to HIV on many fronts. It is unclear how the political upheavals that began this decade will change that. On the one hand, the long-term prospect of democratic reforms could open the possibility of greater women's rights. On the other, the rise of political Islam has brought to the fore conservative interpretations of religion that constrict women's scope, when the very same texts could be read in another light, thereby opening women's opportunities. Already, women have seen their political representation reduced in a number of post-"Arab Uprising" parliaments, notably in Egypt and Kuwait. And it has prompted a number of draft laws that, if passed, would represent a setback for women's rights. Women's opportunities—and therefore their vulnerability to HIV—hang in the balance across the region.





3. LIVING WITH HIV

"Before marriage, I was dreaming to marry a handsome man and establish a small family full of love and affection," said Samira, a woman living with HIV in Algeria. At 19, her dream came true, but at a terrible cost. "After marriage, I moved to his big family house. During this period, I was beaten by my husband." For Samira, the trouble kept on coming. Her firstborn quickly developed health problems. "My baby was admitted to the hospital, and I did not know what to be waiting for. The hospital did all the laboratory tests, without telling me anything," she said. "I was informed that I am [HIV-] positive in the hospital and I didn't know where to go. Both my husband and my son died."

By her early 20s, Samira was a widow, a grieving mother and coping with a serious illness—a heavy burden for anyone to bear, all the harder because Samira did not see any of this coming. For many women in MENA, diagnosis with HIV comes like a bolt from the blue. Very few suspect they are at risk from husbands who, like Samira's, are injecting drugs or having unprotected sex with key populations at higher risk of HIV infection, among them men-who-have-sex-with-men or female sex workers. Because of such "illicit" routes of transmission, wives are often the last to know about their spouse's infection: one study of people living with HIV in Egypt found that two-thirds of men had failed to inform their wives of their diagnosis.[1]

Health and family

Learning about their status is enough to plunge many women into depression. For some, this is because they believe they have been handed a death sentence: many are simply unaware of the possibilities of treatment and long-term survival—provided they can access medical care, by no means a sure thing anywhere in the region. But for others, the bigger problem of coming to grips with HIV is the crushing weight of stigma and discrimination that knows no bounds of age, wealth or class—stigma which studies show change the way they see themselves, and others.[2]

> *I sat in a state of complete withdrawal at home.*
> ***I did not leave home as I was afraid of people.***

Woman living with HIV, **Yemen**

> *One day I was very tired, I tried to introduce my mother to the subject [of having HIV]. During breakfast, I asked her how she would feel about sitting with an HIV-infected person.*
> ***She replied saying she will throw the tray of food in the street and run away to escape. I kept silent, completed my breakfast quickly and went out. Ever since, I did not say anything to anyone else.***

Woman living with HIV, **Sudan**

> *At first, when they knew that I was infected, my family told me not to sleep or sit by the side of my daughter. They took her from me.*
> ***Afterwards, they started to understand and then they told me it is OK, and things went back to normal.***

Woman living with HIV, **Yemen**

Testimonial after testimonial from the women of MENA-Rosa speaks to the formidable social barriers facing those who are living with HIV. HIV is popularly associated with "illicit" practices, and so women who are infected are far more likely to face social rejection than their male counterparts, where a "boys will be boys" mentality excuses behaviours—especially sexual misadventure—that are simply not tolerated among women, and offers men far more support than women in coping with their illness.

The emerging body of research on stigma and discrimination makes for sober reading. In one study from Saudi Arabia, for example, more than three-quarters of survey participants believed that people living with HIV should be isolated from the public and 60% said those infected should be fired from their jobs. In another study of young people in Yemen, Jordan, Kuwait and Qatar, more than three-fifths of respondents believed that having a relative with HIV would tarnish their own reputation. Attitudes were particularly harsh towards women: more than 80% of respondents believed that women living with HIV should not be allowed to get married; more than three quarters thought that women living with HIV should be sterilized and that those who are pregnant should have an abortion.[3]

> *My mother found out about my disease by finding out about the medicine in my fridge; she knew [about the medicine] through the pharmacy.*
> ***She died recently, after knowing this news, from a heart attack.***
> ***I had a nervous breakdown; I was crazy for long time.***

Woman living with HIV, **Algeria**

With these sorts of attitudes doing the rounds, it is not surprising that women living with HIV think twice about disclosing their condition.[4] Some prefer to live in silence, although the burden of carrying such a secret weighs heavy on many. Some worry about the impact that such knowledge will have on family members. Others fear outright ostracism by neighbours, friends and family, and being forced to move away due to social pressure or threats of violence.

Other women, however, find the courage to disclose their condition to family members—usually husbands—and in return, receive vital emotional and material support. Indeed, supportive close relatives often set the tone for other family members to follow their lead. In rarer cases, neighbours and community leaders also turn out to be pillars of strength.

> *Telling people could have a negative outcome such as rejection, but it was a positive for me as I found a lot of support.*
> ***For example, the Head of the People's Committee in the neighbourhood is asking about me frequently. The members also ask about me when I am around, so I live a positive life.***

Woman living with HIV, **Sudan**

> *At the beginning of my disease, my family was afraid of me, but I thank my husband who helps me a lot.*
> ***He did not make me feel that I have any sickness. Even when my family saw me with my husband and noticed how he is responsible for me, they don't ask anymore about me [in a suspicious way]. I found him by my shoulders [supporting me], not afraid of me.***

Woman living with HIV, **Algeria**

For women with HIV, stigma and discrimination are also features of one of the most important aspects of their new lives: healthcare. As a number of studies demonstrate, doctors, nurses and other health professionals across the region are, unfortunately, no less fearful or judgmental when it comes to dealing with people living with HIV than their less educated peers.[5]

The doctor told me,
"You've got AIDS; this means you are not a good person."

Woman living with HIV, **Tunisia**

> *I have a woman's [reproductive tract] inflammation. I went to my doctor whom I have known for a long time. Unfortunately, she discovered that I have HIV.*
> ***Everyone became frightened and the whole clinic was thrown into a state of emergency. They removed the bed sheet and threw it in the trashcan, as well as her instruments. Of course everything was drawing attention to me, and ultimately they rejected me.***

Woman living with HIV, **Jordan**

Such attitudes complicate an already difficult healthcare situation for women in general, and those living with HIV in particular.[6] First and foremost among the daily challenges is access to anti-retroviral (ARV) treatment. Although a number of countries offer free ARVs, treatment coverage varies greatly across the region; on average, only around 10% of patients eligible for treatment are getting the medicines they need. In a number of countries, medications for opportunistic infections are not covered, an expense that few patients can easily afford. Even where the medicines are available, supplies are not always steady; stock-outs are a regular occurrence in a number of countries, with patients changing medications time and again.[7] Those who can't get ARVs sometimes resort to herbal remedies, often with crippling side effects.

> *When they spoke about the treatment, they did not say that it had any side effects or symptoms, nor gave any advice.*
> ***Nobody spoke to us; they would only prescribe the treatment without speaking about anything.***

Woman living with HIV, **Yemen**

Side effects are also a problem for those who manage to stay on a continuous regimen of ARVs, all the more difficult to cope with because few physicians adequately counsel patients. Aside from diarrhoea, deafness, numbness, nausea and other problems, some women living with HIV find the cosmetic changes that accompany some ARV regimens—skin discoloration and weight redistribution—equally hard to deal with. Nonetheless, treatment compliance remains high across the region.[8]

> *I wish that my husband sees me as beautiful;*
> ***I do not want to look ugly in front of him.***

Woman living with HIV, **Lebanon**

While some women do receive clear advice and follow-up from their physicians, this is more the exception than the rule for the members of MENA-Rosa. Across the region, women are forced to pay for their own monitoring—CD4 counts and viral load tests—if they can get them, that is; more often than not, the only machine available is out-of-order, for months on end. Other vital elements of care—psychological counselling, for example—are services that public health systems fail to provide, leaving women living with HIV especially vulnerable.

> *I prefer a female doctor, because we are in a religious fanatic backward community.*
> ***It is not possible to speak to men and, in Yemen, there are not female doctors or nurses; even psychiatric clinics do not exist. We badly need specialized psychiatric physicians, because our condition is just awful.***

Woman living with HIV, **Yemen**

Women living with HIV have other health needs that are equally difficult for them to address. A particular problem for the members of MENA-Rosa, for example, is finding a dentist willing to take them on as patients. Some have found sympathetic practitioners, but others prefer to avoid potential rejection and therefore keep their infection a secret—an unfortunate situation for both patient and healthcare provider.

> *Once I had tooth pain. When I went to the dentist, I told him I had HIV. He told me, "One second please." I was already on the dentist chair and he was about to extract my tooth. He sent in the nurse who said, "The doctor apologizes, as he will not be able to help you." Of course I came out of the clinic crying and totally broken.*
>
> ***After that, I went to the Ministry [of Health] and told them the story. They told me, "Why did you tell him that you have HIV? Don't say that again. Go and get your tooth taken out, as the tools will be sterilized anyway." Due to the pain I had to go to another dentist; I did not tell him anything and I had the tooth removed.***

Woman living with HIV, **Egypt**

Sexual and reproductive life

Sexual and reproductive health is also a pressing concern. Women living with HIV in MENA tend to be infected at an earlier age than their male peers. Given that women in much of the region are married by their mid-twenties and that most women are infected through their husbands, HIV therefore hits them in their reproductive prime. Although fertility rates are falling in MENA, childbearing remains both a strong personal desire and strong societal expectation. So women living with HIV are faced with a dilemma: knowing they have HIV, can they safely have uninfected children?

> ***How can I give birth when my husband is not infected? I cannot harm him with such a disaster.***
> *But if there is a modern medical way, can I get pregnant from an uninfected man and I am infected? Can I give birth?*
>
> Woman living with HIV, **Yemen**

Part of the problem is getting to conception. Many of the members of MENA-Rosa find sex a problem after infection. For some, this is a side effect of their illness or treatment; for others a psychological block, given that sexual intercourse was the way they were infected in the first place. Their anxiety is compounded by their fear of transmitting the infection to their husbands, and by extension, to any co-wives as well.

Very few women, with HIV or otherwise, across MENA have access to accurate and user-friendly advice on sexual health. Less than 70% of pregnant women in MENA have at least one antenatal check up.[9] Only a minority of practitioners are either trained or comfortable in providing sexual health information or care, and scarcely a handful of centers across the region providing anything close to integrated HIV, sexual and reproductive health services.

> ***Certainly the infection affected my sexual relationships.***
> *I no longer have any desire for sexual intercourse, and when I do, I use condoms. I have decided not to have children to avoid the possibility of having a child that is infected, or that I could not financially support him/her.*
>
> Woman living with HIV, **Sudan**

Not suprisingly then, many women living with HIV, even if they can find professional assistance, are faced with conflicting advice and are largely unaware of measures to reduce the risk of infection in any children they may have. Practitioner bias means those couples in need of assisted reproduction can find it hard to secure a doctor who will help them, and in some extreme cases, HIV-positive women have been sterilized, without their knowledge and consent.

When my husband and myself wanted to have a child, we went in order to make a medical operation in a government hospital. The center referred us to a doctor who refused to make for my husband the procedure [to improve his fertility] because of the HIV.

Moreover, the doctor told him that it is not his right to give birth to infected children.

Woman living with HIV, **Jordan**

Women who decide to press ahead with pregnancy can find themselves in tremendous difficulty. Around 20,000 pregnant women across the region are thought to need access to treatment for prevention-of-mother-to-child-transmission.[10] While recent years have seen increases in the numbers of pregnant women on such therapy, notably in Oman and Algeria, across the region, only around 5% of pregnant women with HIV are thought to be receiving the care they need.

> *I was bleeding during my pregnancy and no one helped me until I lost the baby. The doctor closed his telephone, although he is the Ministry of Health / HIV Programme-appointed doctor in the centre.* ***Apparently he did not want to expose himself to dangers. After a lot of suffering, a female doctor (last year student) helped me. When I told her of my infection, she asked me to remain silent and not to tell anyone else. May God bless her.***

Woman living with HIV, **Sudan**

Delivery also poses tremendous challenges. Just finding a hospital that will admit pregnant women once their HIV-status is known is a formidable challenge. While some women have been lucky enough to find sympathetic practitioners and facilities—often with the assistance of an NGO—others face fierce discrimination and frank maltreatment at this most vulnerable moment in their lives.

> ***I entered the hospital to deliver my baby; they wrote "infection" over my head, until the social assistant came and removed it.***
> *Still, not one of them has dealt well with me in a good way; they even started to blame me, and told me that I have no need for children.*

Woman living with HIV, **Morocco**

But these women are, in some ways, the lucky ones—knowing their HIV-status, they have a chance to act. Across MENA, women are watching their children die, unaware that their offspring are infected with HIV, unwittingly transmitted to them in utero and through breastfeeding, by their own mothers, who are often only diagnosed once their children are ailing.

I lived with my husband nearly five months, and in the sixth month, I conceived a child. I was happy because of the joy of something beautiful growing inside my womb. I was tired a lot because of my pregnancy, but I used to wipe the pain with the hope of seeing my baby. I gave birth to a beautiful boy; his hands were very small and soft. I dreamed of a future great life and promising joy.

Three months after his birth, the baby got sick. When the words of the doctor came out, declaring his disease [HIV], they were like a thunder on my ears. The world darkened in front of my eyes, I lost hope in life and lost the beautiful dream.

Days passed and my son died. I accepted his loss after a lot of help from my family and praying to God.

Woman living with HIV, **Sudan**

Children who do survive face plenty of medical problems. There are an estimated 40,000 [27,000 – 52,000] children living with HIV in MENA.[11] Because of the low generalized prevalence of HIV in most countries in the region, they are still a rarity and as such, there are few formal facilities to care for their needs, all the more pressing if they have been orphaned by HIV.[12] For mothers with HIV who cannot breastfeed, for example, securing a safe, continuous and affordable supply of infant formula is a real problem. There are few specialists in paediatric AIDS in MENA, and little access to children's formulations of ARVs and other medications.

I started the treatment in an unjust way, may God punish everyone in the Ministry of Health. They made the test for me once and did not care to tell me come and take the treatment, neither for myself nor for my daughter. *She was one and half years old and the girl was dying every day and nobody did anything, neither for me nor for her. After that my daughter died and she was one year and eight months old and nobody told me why she died. All I knew was that she had the disease and I did not know there was treatment. As I was very tired after the loss of my daughter, I remained silent forever.*

Woman living with HIV, **Egypt**

Like their mothers, children also bear the brunt of stigma and discrimination, especially if they themselves are infected. Case-in-point is the experience of Nasreen, a woman living with HIV in Tehran, whose husband died of AIDS, leaving her with two sons, the youngest of whom is also has HIV. "After my husband's death, I don't know how, but the school found out about my son's illness and expelled him. At about the same time my immediate family found out about my illness, and from there news spread to the whole 'clan'," she said.

With the help of a local NGO, Nasreen was able to fight her son's expulsion, but reinstatement in school in some ways only added to his difficulties. "The problem became increasingly difficult, because it was no longer a matter of dealing with the school administration. We now had to deal with the parents and the other schoolchildren, who had by then found out about my son's illness; no one played with him, he was teased and called 'AIDS Kid', and the other children would run away from him." News travels fast, even in big cities, and soon the whole neighbourhood was shunning her son.

Constant rejection took its toll on Nasreen's youngest, and he reacted by skipping school, in the end losing three years of attendance. With counselling and care, her youngest son is getting back on track. Now, however, it's her firstborn who is causing her anxiety. "My elder son, currently a student in Law, is worried about the future, whether or not he should reveal his mother's and brother's illness to his fiancée," Nasreen explained. "Given that everyone in the neighbourhood is aware of our situation, he is continually asking me to change our home, because he is afraid that his potential in-laws would block the marriage if they came to the neighbourhood to investigate our family's background."

> *"At birth, I was in a private hospital (the only one which agreed to take me); they knew that I had HIV. I had a natural birth (no surgery) paid for by Caritas [an Egyptian NGO] and they helped me with everything—the child formula milk and diapers until he reached one year and a half.*
>
> ***Caritas were the ones who brought the medicine to the child (which he took for one month) and they also took him for the testing. Thank God, he is not infected."***

Woman living with HIV, **Egypt**

Community institutions

Too often in communities across MENA, stigma is buttressed by interpretations of religion, which turn faith into a tool of oppression rather than what it can be, a source of generosity and compassion. Religion, with its emphasis on the protection of life and health and its messages of mercy, tolerance and understanding, can be a powerful force to improve the lives of people coping with any illness. Beyond spiritual support, religious institutions and endowments can also offer people impoverished by disease material support—food, shelter, financial aid.

On a personal level, religion plays an important role in the lives of men and women across MENA; as surveys show, more than 90% of people living in countries in the region consider religion a key part of their daily existence.[13] For women living with HIV, faith can be, at first, a burden, as religious guilt for past acts—say, drug use, or sex outside of marriage—weighs heavy on many. But for others, a belief in God and His will can be, in the end, a blessing, helping them to come to terms with adversity.

> *After my infection, I started to pray and ask God for forgiveness.* ***Because this is a trial, and God will forgive all my bad deeds.***

Woman living with HIV, **Yemen**

> *I suffered deafness, diarrhea, fever, and then I had some depression when I wanted to end my life. I tried to hang myself three times and I also connected myself to an electric wire.* ***I told myself, "What do I want from this world? My children do not want me and left me alone."***

Woman living with HIV, **Yemen**

Faith in God is one thing, faith in religious institutions quite another. HIV poses particular challenges for religious leaders across MENA, because of its main routes of transmission—sexual intercourse and unsafe injection practices—and the populations in which the epidemic is currently concentrated, among them sex workers, people who inject drugs and men-who-have-sex-with-men. Drugs, sex outside of marriage and sodomy are all behaviours condemned by MENA's major religions—Islam, Christianity and Judaism—carrying hefty penalties in religious law and often, by extension, national law as well.

Part of the problem is ignorance: religious leaders are often as ill-informed as their communities about the ways in which HIV is transmitted, and automatically associate it with "illicit" practices.[14] But often it is reputational risk that is the bigger issue: religious leaders' own fear of being seen to be encouraging unacceptable behaviours by, for example, advocating condoms, thereby running the risk of rejection by their own communities.

> *I work in a mosque, and I am afraid that my infection is discovered. I work with women studying Qur'an, but I do not talk with them about AIDS for fear of their reaction.* ***Even the imam does not speak about this disease; he speaks about sex and drugs [things to be avoided].***
>
> Woman living with HIV, **Algeria**

As a consequence, women living with HIV in MENA have mixed views on the role of religious leaders in offering them support and counsel. Many see them as judgmental and unhelpful, sometimes based on the hard-won experience of having tried, and failed, to seek their assistance, others based on the assumption that religious leaders are just like everyone else, and that stigma, rather than sympathy, will inform their response. The standard message—be chaste, avoid sin, pray and seek God's mercy—lacks practicality for, say, a divorced housewife who is infected, with children and no other means of support, who has turned to sex work to survive and is seeking advice about what to do next.

Given the central role of religion in MENA—from political to personal life—changing the attitudes of religious leaders is vital. Over the past decade, there have been a number of initiatives to better inform religious leaders about HIV and AIDS, providing them with opportunities, in workshops and projects across the region, to interact on a one-to-one basis with populations most at risk of HIV.[15] Such efforts have yielded some banner successes, such as the Djibouti Declaration of 2007, in which local religious leaders endorsed condoms as a means of family planning and HIV prevention. But more important are the small-scale triumphs, in which religious leaders and people living with HIV get to know each other's needs and constraints, building personal relationships that enrich both. The challenge lies in translating this understanding from the private to the public space, and empowering religious leaders to speak out, with the same compassion and pragmatism, to the community at large.

> *I had an experience with religious leaders. After giving a testimony without hiding my face, in the company of two infected girls, I found a great support from a religious leader (an imam) in an Arab state.* ***These people were affected by my testimony, and asked me to resort to religion, because it relieves suffering.***
>
> Woman living with HIV, **Yemen**

Organized religion isn't the only institution in which women living with HIV lack trust. There are 15 countries in the region that report having laws and regulations to protect people living with HIV from discrimination, and several others have draft legislation in the works.[16] However, many women living with HIV are either unaware of such laws or find little recourse to, or help from, them. This is especially true of most-at-risk-women, among them sex workers, transgendered women and people who inject drugs; only four countries in the region explicitly protect the human rights of vulnerable or marginalized populations, for all the fine words in national constitutions.[17]

> *When they took my child from me, my mother-in-law threatened me.*
> ***She said, "If you sue me, I will stand in front of the judge and tell him this woman has HIV."***

Woman living with HIV, **Egypt**

There are welcome attempts in a number of countries in MENA, under the aegis of the International Development Law Organization, to provide legal services and improve access to justice for people living with HIV and key populations at higher risk of infection.[18] But these are still small-scale and finding the funding, as well as a steady supply of willing and able lawyers to train for such work, isn't easy. And so, for many women living with HIV, the law is seen as little help in dealing with their daily struggles, not just because they are women, or that they are living with HIV, but because many live in states where legal systems do little justice to the those most in need—the poor, the socially marginalized, the worst educated or least powerful. Making the law work for them will be one of the greatest challenges, and most meaningful rewards, of the political upheaval now shaping the region.

> *The infected person does not find any support when he seeks law. We hear that law would not support you and will judge you with the maximum punishment.*
> ***Everyone says that we are criminals and that we have no rights.***

Woman living with HIV, **Morocco**

The one institution that many women living with HIV do have confidence in is the one they are helping to create themselves: civil society. There are dozens of NGOs across MENA reaching out to those living with HIV, most of them staffed by people who are themselves positive and best understand the needs of others in similar straits.[19] Many are grouped under the umbrella of RANAA, a MENA-wide network of NGOs focused on HIV, which provides groups with technical support on issues such as planning, management, monitoring and evaluation and communication. Such assistance is badly needed in the region, since civil society has been repressed for years in many countries and now struggles in many parts to secure its place in the emerging democratic order.

> *I work in an NGO that fights AIDS. I have attended several support groups, either inside Morocco or abroad.* ***I have some friends outside Morocco, this encouraged me and made me steady, able to fight the infection and live with it.***
>
> Woman living with HIV, **Morocco**

NGOS on the ground are making a difference to the lives of women living with HIV.
Such organizations are indispensable to women looking for voluntary and confidential HIV testing and counselling, and to get and stay on medication—all the easier if the NGO is itself licensed to distribute the medicine. Such groups are also a vital point of referral to healthcare providers who are known for both their competence and their compassion towards people living with HIV. In a number of countries, NGOs also offer home-based visits and palliative care. NGOs are also providing vital information and prevention tools—notably condoms, which many women are too embarrassed to buy themselves.

For some women, NGOs offer employment, the one place people actually welcome HIV-positive workers. They are also a small but rising voice in political advocacy, fighting for greater legal protection of people living with HIV. For most-at-risk women, such as sex workers, these associations are one of the rare places they can find medical, social and legal services. They also provide a welcome space for women to talk, honestly and openly, about their daily struggles, however personal and however painful. Indeed, fellow support groups members—not family, not friends—are often the only people to whom women living with HIV feel comfortable disclosing their condition.

> *ALCS [Association for the Fight Against AIDS] is the one which supports me in this regard. It stands beside me and comforts me.* ***A lot of time when I feel down, I come to the NGO. I find people like me, I talk to them and each one of us forgets his concerns.***
>
> Woman living with HIV, **Morocco**

A moving picture

Movies and soap operas are widely watched across the Middle East and North Africa, where roughly 70% of households in most countries have access to satellite TV.[20] Women—particularly young women—are avid viewers; in Egypt, for example, more than 95% of ever-married women aged 15-49 watch television at least once a week, and for more than 90% of men and women, TV also represents their main source of information on HIV and AIDS.[21]

Entertainment media, therefore, have powerful role in shaping people's attitudes towards HIV and those living with the infection. Unfortunately, HIV on screen is usually an unhappy sight, generally depicted as the just deserts of those who have defied religion and social norms. In Egypt, films and TV are routinely cited by women living with HIV as stoking stigma and discrimination.[22]

Asmaa, an Egyptian feature film released in 2011, aims to change all that. Asmaa tells the story of a woman who has been living with HIV for more than a decade, having been infected by her husband. The plot centres on her efforts secure lifesaving surgery, effectively out of reach because doctors either refuse to touch her, or judgmentally demand to know how such was infected, implying a distinction between "good" and "bad" HIV.

The film shows the hard knocks of Asmaa's life: the tragic circumstances which led to her infection; her fear of disclosure, leading to conflict with her father and daughter; her precarious living, which is taken away when her employer learns of her condition; and the difficult choice she faces in order to secure the operation she so desperately needs. But the film is also full of touching moments of humanity: the support Asmaa receives from other men and women living with HIV: her dream of seeing her daughter happily married and her own chance at romance: her unshakeable faith in God and her quiet dignity in the face of so much hardship and injustice.

The director, Amr Salama, based the film on the lives of people living with HIV, whom he had the chance to work with under the auspices of UNAIDS Egypt. While Asmaa is a composite of many of their life stories, sadly the central element of the plot is all too true: the film is dedicated to an Egyptian woman who, in fact, died from medical neglect, unable to find treatment because of her HIV status.

Hind Sabry, a Tunisian actress who plays Asmaa, thought twice about taking on the role. "It's a very complicated part," she explained. "It is very risky for an actress to be associated with AIDS in the Arab world."[23] But the more Sabry got to know the women whose lives she was portraying, the more she appreciated the importance of the film. "I'm very proud of all of us because it wasn't easy with all the stigma," she explained. "It's media-made, the stigma about AIDS, and we're trying to answer the stigma with a new form of media, non-judgmental, not clichéd."

Almost half a million Egyptians saw the film during its theatrical release, and Asmaa has reached international audiences through film festivals worldwide. The movie triggered an avalanche of media coverage: hundreds of print articles and scores of TV shows covering the film's key issues—confidentiality and other rights of people living with HIV, women's empowerment and medical ethics among them. Asmaa is clearly making a difference: one online survey found that three-fifths of respondents took a more positive view of people living with HIV after watching the film.[24]

In one recent screening, at Cairo University Medical School, students erupted in cheers when Asmaa spoke directly to the camera. "I will not die from my disease," she said. "I will die from the disease you [society] have"—that is, stigma and intolerance. Asmaa is just one small step, but it is in the right direction, on the long road to changing public perceptions of people living with HIV.





4. WOMEN ON THE EDGE

Hard labour: sex work

Sex work is one of the most diversified industries in the Middle East and North Africa, offering a wide array of services to a vast range of clients at a variety of prices. Malika, a woman living with HIV from Oran in Algeria, is just one face of this booming trade. Married at 20, her union was a disaster from the start. "I was beaten and cursed by [my husband] all the time. He couldn't talk to me without fighting. Life became unbearable with him." After fits and starts of separation and reconciliation, Malika eventually divorced, and moved back home.

In her mid-twenties, like many young people, through friends, she got to know the city's nightlife. "I was impressed with their world and dresses," she said. "Especially after I was deprived of everything." So Malika took off her hijab, and entered the sex trade. The money was relatively good, by local standards—around 2,000-3,000 Algerian Dinar (around USD 25-40) a "pass"—and it was quickly spent. While her family depends on Malika's income, its real source is not something that she has disclosed. "I explained to my family that I work in the information technology field, and that I do some business deals which allow me to make some extra money."

A couple of years ago, Malika's health began to falter, with dramatic weight loss and other symptoms. She suspected it might be HIV, having had unprotected sex with a boyfriend who suffered the same signs. Nonetheless, her test results were a shock. "Since I knew I am infected with the virus, my life totally changed and my view of life changed too. When I was married, I suffered from poverty and the treatment of my husband to me. I thought that the meaning of life is money," she said. "But now I understand life very well. I would advise women to be close to God Almighty, and don't follow their whims."

As study after study in countries across the region shows, Malika's experience is far from unique.[1] Poverty—often brought on by divorce and the need to support kids family instability, including a history of domestic violence; abuse by clients, pimps and police; and poor access to reproductive, sexual and other healthcare services—are realities for female sex workers.

Like most women in MENA, knowledge of HIV and STIs among female sex workers is generally limited. Multiple clients a day is generally the rule and condom use varies, from a low of 25% of female sex workers in Egypt reporting condom use with their last client, to more than half in Morocco claiming protected sex. A number of economic, legal and socio-cultural considerations conspire to make women agree to unprotected sex, even when they know the dangers.

> *Only my sister knows. I do not tell anyone because they call me bad names.* ***I better isolate myself.***

Woman living with HIV and sex worker, **Tunisia**

While forms of legalized sex work exist in a handful of countries in the region—most notably Tunisia—most sex workers are operating outside of this state-sanctioned context and therefore they, and all those who aid and abet the trade, are breaking the law—not something which encourages them to come forth for testing or treatment of any problem, let alone one as stigmatizing as HIV. Where systematic research has been done, the upshot is significantly higher rates of HIV infection among female sex workers than in the general population. This is well documented in Djibouti and seen in several other countries in the region as well.

In a number of countries—among them Morocco, Tunisia, Algeria, Egypt, Jordan, Lebanon—there are NGOs are trying to address this gap. The work isn't easy: such is the stigma associated with both sex work and HIV that even outreach workers are at a risk, from police harassment, arrest and social opprobrium. But there are notable successes—among them ALCS and OPALS in Morocco, which have one of the most extensive networks of outreach to female sex workers, and in Djibouti whose small sex worker-run project is a model for neighbours across the region (see box).

Malika too is playing her part by speaking out, sharing her hard won experience with others and counselling sex workers on HIV prevention and testing.

> *My wish: to live like others, to be spoken to normally and* ***no one is afraid of us.***

Woman living with HIV and sex worker, **Tunisia**

Sisters, doing it for themselves

There are more than 1,300 female commercial sex workers and *makalifs*—single women engaging in transactional sex—in Djibouti.[2] Their services cover a wide range of tastes and tariffs: from high-end escorts in hotels and bars catering to Western and Arab men for upwards of 5,000 Djibouti Francs (around USD 30) a "pass"; to Djiboutian, Somali and Ethiopian women having sex in tiny rooms with passing truck drivers for as little as 1,000 Djibouti Francs; to desperately poor women selling themselves on the street for less than a quarter of that amount.

Djibouti's female sex workers occupy top spot in the country's HIV infection charts, with a prevalence of more than 15%, 10 times higher than that of the general population.[3] Small-scale studies suggest high levels of condom use among female commercial sex workers, more than 70% saying they used them with their last client. But among the *makalifs*, condom use is irregular, at best, in part because women find them hard to obtain; in part because they can attract more clients, and more money per transaction, without them; and in part because it is difficult to negotiate with clients, who hold the power. All classes of Djiboutian sex workers are vulnerable to HIV, with risky sexual practices including unprotected anal relations and dry sex.[4] Moreover, these women are in demand, with up to 60 partners per sex worker per week according to some estimates.[5] Their lives are tough, alcohol and khat helping them to get through the day—none of which is conducive to safe sex.

One project trying to change all that is Soeur-à-Soeur. Under the auspices of Djibouti's Ministry of Health, this peer-to-peer NGO involves older sex workers taking the lead in helping to inform and protect their counterparts from HIV and other occupational hazards. The peer educators of Soeur-à-Soeur seek help from other groups working on health, education, nutrition, thereby catalyzing a nexus of four NGOS and several public sector organizations assisting sex workers. The 50 peer-educators of Soeur-à-Soeur are reaching out to both commercial sex workers and, critically, the harder to reach *makalifs*, promoting and distributing condoms, and referring women for medical attention and HIV testing. On any given day, up to 100 female sex workers are benefiting from Soeur-à-Soeur's outreach, including self-help groups to share their problems and coping strategies.

The Soeur-à-Soeur project has proved so effective that it is even reaching beyond its core constituency to other key populations, such as men-who-have-sex-with-men. The Djibouti government has made a legal commitment to address the challenges of not just those living with HIV, but those at greatest risk, including sex workers explicitly. Initiatives like Soeur-à-Soeur point the way to scaling up such efforts, not just in Djibouti but across MENA, in which female sex workers can truly help themselves.

On the sharp end: women who inject drugs

Across MENA, roughly 0.2% of the population is thought to be injecting drugs, on a par with the global average.[6] In several countries—including Egypt, Iran and Morocco—people who inject drugs occupy a top spot in terms of HIV prevalence, with infection rates in excess of 5%. They also account for more than half of HIV transmission in a number of states in the region, among them Libya and Bahrain.

Where rigorous research has been done, risky practices among injecting drugs users are evident. In Morocco, for example, while more than two-thirds of people who inject drugs say they used clean equipment when last shooting up, less than a third used a condom at last sexual intercourse and barely 10% have been tested for HIV and know their results.[7] All this leaves the sexual partners of people who inject drugs on the frontlines of infection.

Case-in-point is Maryam, a young woman in Tehran. "I am a 26 year-old girl who has lived through two lives already: one took my youth, the other my health," she said. At 19, Maryam married someone in her hometown, but the union quickly fell apart, in part because of her husband's drug addiction. Maryam ran away to Tehran, where she lived on the street for a time (see box).

At a shelter where she eventually found refuge, Maryam met the man who would become her next husband, an ex-addict who was working to help others overcome their addiction, and saw "a bright future" with Maryam. But her husband's past life was hard to shake. His failing health took him to hospital where he was diagnosed with a deadly trio: hepatitis C, cerebral toxoplasmosis and HIV. Maryam, then heavily pregnant, was also tested. "My worst fear was in due course realized: I was infected with HIV." Maryam is not alone: in Iran, HIV among the female partners of people who inject drugs is running at around 4%.[8]

Luckily, Maryam's child was born HIV-negative. This is the one piece of good news in her otherwise sad tale. Soon after being diagnosed, her husband resumed his habit, and now, says Maryam, "He just spends his time lying around the home like dead flesh." Faced with such hopelessness, Maryam is trying to break free. "The single thought that now shadows me day and night is how my life will unfold after my divorce, with a two-year-old child on my hands, poor health, and the stigma and discrimination of my illness."

Although Maryam's situation is bleak, at least she is able to speak out. For all the stigma and discrimination surrounding HIV, she is widely seen as a "victim" of her husband's "mistakes". Further in the shadows are women living with HIV whom themselves inject drugs, whose habit is often connected to sex work, and time in prison for both prostitution and drug-related offences—baggage which is hard to bear.

In studies of women using drugs in Morocco, Egypt and Jordan, the risks are apparent.[9] Early marriage—a known risk factor of HIV among women—is accompanied by the early introduction to drug use by their husbands; others owe their debut to boyfriends or clients. Women often trade sex for drugs, either of their own accord or under pressure from their male partners. The greater stigma associated with female drug use means little family support; while male addicts are often helped by their families into therapy, their

female counterparts get no such assistance, shunned at best, abused at worst by other family members. Such is the stigma associated with female drug use that few are willing to seek treatment, even where it is available without moral judgement, as in specialized programmes for female drug users in Morocco, Egypt and Jordan. Condom use is as hard for female drug users to negotiate as for any woman, and access to adequate reproductive and sexual health services, especially during pregnancy, is rare.

The regional leader in addressing the risks associated with injecting drug use, including that by women, is Iran. The need is great: there may be as many as 230,000 people who inject drugs in the country, according to official estimates, among whom just under 5% are women.[10] For more than a decade, Iran's "triangular clinics" have been providing HIV voluntary counselling and testing (VCT); condom and sterile syringe distribution; education and counselling on addiction, HIV and sexually transmitted infections for clients and family members; diagnosis and treatment of STIs, as well as antiretroviral therapy and treatment for opportunistic infections. These clinics are complemented by an extensive network of private clinics, drop-in centres and NGOs providing harm reduction services, including clean syringes and methadone maintenance therapy.[11]

Since 2008, Iran has focused explicitly on the needs of most-at-risk women through more than 20 Counselling Centres for Vulnerable Women.[12] The centres, staffed entirely by female physicians, psychologists, social workers, midwives and other health professionals, provide a range of services for female sex workers, female drug users, as well as the wives of drug users and prison inmates. Beneficiaries can avail themselves of information on HIV prevention and treatment; free needles, syringes and condoms; routine testing and treatment for STIs, family planning services as well as some of life's little comforts—a hot meal, a bath and other basics. The centres also do outreach, offering education and harm reduction on the ground, as well as encouraging at-risk women to visit them. Not all communities welcome the initiative in their backyards, and there has been resistance in some regions. Elsewhere, though, the project has met with acceptance from locals and appreciation from beneficiaries who have few alternatives—a friendly, safe haven from their harsh lives beyond the centres' doors.

Beyond borders

MENA is on the move. Countries in the region send forth an estimated 20 million emigrants and receive almost 25 million immigrants a year, both from within the region and the wider world.[16] Migration brings rewards to the millions moving for better jobs than they can find at home, but it also carries risks, among them HIV.

Just ask Dowlat, a woman from a village near Cairo. At the age of 23, Dowlat married her third husband, a fellow Egyptian more than twice her age who had worked in Saudi Arabia for thirty years. Soon after their marriage, he died of AIDS-related causes; only some time later did Dowlat get herself tested, only to discover—to her surprise and dismay—that she and her child had HIV.

Dowlat is not alone; women across the MENA region are unwittingly being infected through their husbands who have acquired HIV while abroad. As one member of MENA-Rosa from Lebanon put it bluntly, "My advice to women is that if her husband was living abroad, before having relations with him, he should do [HIV] testing."

Men account for more than half of migrants to countries in the region. Far from their families and the norms of home, the risks to HIV can multiply, including unprotected sex with sex workers—or engaging in sex work themselves—and injecting drug use. Moreover, in many centres of migration within the region, there is little outreach on HIV education and prevention for foreign workers. Nor is there much incentive to seek advice and information. A dozen countries in the region have mandatory testing of migrants, who are deported if discovered to be HIV-positive.[17] Quite aside from flouting international human rights norms, by driving HIV underground, such policies do little to help the communities they purport to protect.

But it's not just men who are vulnerable when it comes to HIV and migration. Amat, member of MENA-Rosa in Sana'a, knows this at first hand. "I have no common skills, but God gave me a good voice. I was a singer, in Saudi Arabia, and I was living very comfortably," she explained. "But after I got sick [with HIV], we returned like beggars. They kicked us out of the Kingdom, so I came here to work in Yemen. My work is very limited as my health has deteriorated so much."

Women migrate throughout MENA and are particularly visible in Gulf Cooperation Council countries, where they work in domestic service, tourism and other industries. Most women come of their own accord; there are, however, those who are trafficked for sex work and other labour. Female migrants are not just visible; they are vulnerable too, and at particular risk of HIV infection.[18] In Sri Lanka, for example, around 40% of identified HIV infections among women are associated with working, mainly as domestics, in the Persian Gulf region.[19]

Workers are not the only mobile population in MENA. The region is home to more than 7 million refugees and internally displaced individuals, giving it top spot in the international rankings; in most countries of the region, women account for 40% or more of such displaced persons.[20] Conflict—be it long running tensions between Palestine and Israel, recent wars like the invasion of Iraq or the latest political convulsions, among them Syria's bloody clashes—have sent people fleeing from their homes. But their destination is often hardly better than their point of departure. Even those with legal entitlement can find it hard in practice to access adequate health services and housing, clean water and sanitation. What is often in ample supply is poverty, from a loss of land, livelihood and social support. Nor do refugees necessarily face a warm welcome from the locals, who are themselves struggling to make do with what they have.

All the factors that drive people to leave their homeland are what make refugees, and in particular women, vulnerable to HIV, including heightened exposure to sexual violence and poverty that may push them into sex work.[21] Among female Sudanese refugees, for example, HIV rates range from 1-5% in their countries of refuge.[22] For those who are infected, the going is hard. "I am not from Yemen, I am a refugee," said Fouzia, a woman living with HIV in Sana'a. Fouzia paid an exorbitant sum to get herself tested for HIV, because no other

facility would take her. "I went to some organization as a refugee and they said, "There is nothing to be done. We used to send refugees to [such-and-such a] hospital, but they refused to make the test because there is not support from the refugees [organizations] or the government." Fouzia is in a difficult position. "Thus I am not able to make any test or to know how much immunity I have. I am not able to use the treatment because I am confused and I cannot do anything." As peoples across MENA increasingly hold their governments to account, how well they can provide for Fouzia, and others like her at the margins, will be one of the key measures of their success in rising to the challenge of HIV.

Living rough

Maryam's time on the streets was one of the hardest of her life. Of all the women on the margins of MENA, street girls are teetering on the farthest edge of society; so much so that there is very little information about street children in most countries in the region. One exception is Egypt, where decades of research and activism have brought the troubled lives of the country's estimated 200,000 or more street kids to light.

In 2010, Egypt's bio-behavioural survey of key populations at higher risk of HIV infection found a prevalence of 0.5% among the teenage street kids it studied.[13] It also uncovered plenty of risk factors, particularly among street girls: a quarter of the young women had a history of non-injecting drug use, and more than 10% consumed alcohol on a weekly basis. More than 15% of street girls reported previous sexual activity, making their debut around age 14, half of them for money over the past year. Almost 40% of the girls had never attended school, barely a quarter of the street girls had heard of HIV, and of them, scarcely 5% had been tested. Condom use was negligible, but forced sex was all too common, with almost a third of street girls reporting forced relations in the past year.

Others research has fleshed out these risks in daunting detail. In a study of more than 800 street kids, more than 80% of the girls in Cairo aged 12-17 had been living on the street for more than a year and around half had no contact with their families.[14] Virtually all the girls surveyed in Cairo and Alexandria had experienced violence and as many as 90% of the 15-17 year olds had a history of sexual abuse. Self-declared sexual activity was much higher in this study, with almost three-quarters of girls in Cairo reporting previous sexual activity, more than a third with multiple partners.

Similarly disturbing patterns are evident among street kids in Sudan, where HIV rates exceed 2%, and in Iran, where up to 9% of street kids, who also use drugs, are thought to be infected.[15] With such risky behaviours the norm for street kids in Egypt, it would seem only a matter of time before HIV, once in the population, spreads. There are however, a number of NGOs in Egypt taking action. Among the most active is Hope Village whose drop-in centres, short- and long-term shelters, and mobile units, are reaching roughly 8,000 street children in Cairo and Alexandria a year. The society tries to raise HIV awareness among its beneficiaries, and broach the issue of safe sex without raising hackles of religious conservatives who object to any talk of sex outside of marriage. Such objections also make condom distribution to street kids difficult, not to mention the precarious security situation after the uprising of 2011 that has pushed street kids even further to the edge.

While changing the attitudes and behaviours of street kids isn't easy, altering society's view is an even tougher task. "People sometimes feel sympathy to these children, but when it comes to integrating them into society, they act differently." says Abla El-Badry, director of Hope Village. "Why are [street] children so aggressive with the community? Why do they feel happy when they do any harm to you or to me? Because of the aggression inside of the children, [which is] because of us. Changing the look towards them, this is the first step toward solving the problem." And solving that problem could go a long way to stopping HIV among street girls, before it really gets started.



5. WHAT WOMEN WANT

At 25, Fatima, who lives in Morocco, has experienced more of life than women twice her age. Married at 20, she lost her first born son at four months of age; soon thereafter she discovered that she was infected with HIV.

Fatima is one of the lucky ones. While shunned by friends and family, her husband has stood by her through it all. "My husband supported me," she said. "He believes it is God's will and he will not leave me until death." The couple went on to have two daughters, and both they and her husband are not infected. "My hope is able to take care of my daughters. The oldest one wants to be a doctor," she said proudly. "She always says, 'I will be a doctor and cure you, Mom. You will not have to take this medicine anymore.'"

Such are the dreams of the members of MENA-Rosa. Many they share with millions of other women across the region to whom HIV is just a string of letters, not a daily reality: marriage, children, grandchildren, a happy and healthy life for themselves and their families. But for many, HIV has altered life priorities. "Before my infection, my wish was to work, live, be happy, travel and have money," says Hiba, a 30 year old from Lebanon, who has been living with HIV for five years. "Now, the money / financial situation has no longer any impact on my life, health is the most important thing to me." But for others, in less fortunate circumstances, money does matter; their illness means that food, housing and healthcare are daily struggles.

UNAIDS has neatly summarized the challenges facing women living with HIV around the world, challenges which equally confront women in the Middle East and North Africa:

"Unbalanced power relations, lack of access to services, economic and legal empowerment differentials between men and women, sexual coercion and violence and entrenched gender roles limit the ability of women and girls to exercise their rights. HIV-related stigma and discrimination disproportionally affect women and girls, constraining their ability to access services. HIV-positive women and girls are less likely to have access to services, disclose their status or negotiate safer sex for fear of being mistreated, rejected or experiencing violence. Moreover, women and girls carry a disproportionate and

debilitating burden of AIDS-related care, especially in places with weak health and other public sector services. In addition, girls miss school and women are forced to leave paid work due to factors such as early marriage, pregnancy outside marriage and socially ascribed requirements to care for the sick, thereby deepening the poverty and economic dependence of women, reducing their ability to participate in public life and hindering their socioeconomic, cultural and political potentials."[1]

In their fundamental interests, women living with HIV are no different to their fellow citizens seeking a better life in the shifting political order. The human rights to which people in MENA aspire, and to which those in emerging democracies must hold their new governments to account, are essential for all. But achieving these rights is a complex process, involving action on the international, national, regional and local stage and the coordinated efforts of many actors—public and private sector, and civil society—across multiple fields. For women living with HIV to get their share of the promised gains, especially those on the outer edge of these margins—poor, rural, uneducated, disabled, displaced, or members of ethnic, religious or sexual minorities, or those disdained because of drug use or sex work—they must be central to the efforts to improve their lives, from planning to implementation. The task is vast, but the women of MENA-Rosa know exactly where to start:

- Guaranteed female school attendance, not just through legislation and enforcement, but by making school more affordable and accessible to girls' families. Improve the quality of school education so that female graduates can compete for jobs, avoid early marriage and other situations that increase vulnerability to HIV.

- Guaranteed access to the best available HIV prevention measures, including youth-friendly life-skills and reproductive health education and services; access to prevention commodities, and voluntary testing and counselling for women and girls, of all ages, linked to awareness campaigns for women on HIV and STIs, all available at discreet, female-friendly venues.

> *I wish that the medicine wasn't being changed all the time, and that the department of infectious diseases was more organized.*
> ***I wish there were clean, private rooms, and that patients did not have to just sit around, as by a grave, waiting for their death.***
>
> Woman living with HIV, **Algeria**

- Sustained quality treatment and support, especially appropriate antiretroviral medications and clinical tests, free at the point of delivery. Reform medical school curricula, and continuing medical and health education, to include instruction and training on the needs of women affected and living with HIV, to improve the quality of services and reduce stigma and discrimination among healthcare professionals.

- Systematic collection and analysis of information and data on how the epidemic and social and structural factors affect women and girls in the region, and strategic use of such data in programmes to prevent new infections and to support those living with HIV.

- Address the needs of women at higher risk of HIV infection, including female sex workers and women who inject drugs, through enabling legislation, policies, and comprehensive packages of woman-friendly services.

> *The work of support groups is necessary and essential, because within the group one can reveal many things.*
> ***So the number of these groups must increase in order for everyone of us to speak.***

Woman living with HIV, **Morocco**

- Ensure that national HIV policies link to legal reforms on property rights, inheritance, women's mobility, national identity registration and other essential documents that promote equal access and punish discrimination.

- Support women as caregivers with cash transfers, training and other programmes that recognize and reward the value of their work, and make women aware of their labour and economic rights, and how to realize them in practice.

> *I am a woman living with HIV. I would love to have a project with a stable income.*
> ***I want a good project because I have the ability to do something good in this life.***

Woman living with HIV, **Jordan**

- Remove restrictions on entry, stay or residency based on HIV status, which impede the ability of women living with HIV to earn a living, limit access to treatment and increase vulnerability to infection.

- Develop strategies to address social norms around gender and sexual relationships in ways that reduce gender-based violence and protect women living with or at risk of HIV from violence, including marital rape and so-called honour crimes. Empower women to speak about gender-based violence and access services that prevent such violence and alleviate its impact on the women affected.

> *We can fix this situation through awareness campaigns, where we can tell the community that HIV or AIDS is an acquired disease, such as the rest of diseases.*
>
> ***Many diseases are much more serious and can be transmitted sexually, but the community also has a problem that AIDS could be a vice because it is transmitted sexually or through needles. We can correct their point of view through awareness using the media and television.***

Woman living with HIV, **Lebanon**

- Engage religious leaders and institutions in eliminating stigma against people living with HIV, and other practices that discriminate against or are detrimental to women. Challenge cultural constructs of masculine dominance of women within marriage, which put women at risk of sexual violence and other violations of their sexual and reproductive integrity and independence.

- Involve men at the family, community and governmental levels in projects and policies that protect the rights of women, including those living with HIV. Promote gender equality at the highest levels of policy-making, through representation of women in political and legal executives, in both public and private sectors.

> *I hope, in future, the people become more open so that the person living with HIV does not become isolated from society.*
> ***We did not run towards this disease, nor choose to have it.***

Woman living with HIV, **Algeria**



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This report was written by Shereen El Feki, author and Vice-Chair of the Global Commission on HIV and the Law.

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NOTES

Part 1: **Introduction**

[1] In this report, the MENA region, as designated by UNAIDS, encompasses 21 countries: Algeria, Bahrain, Djibouti, Egypt, Iran, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Occupied Palestinian Territories, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates and Yemen.
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Part 5: What Women Want

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