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In the three decades since the first AIDS case was identified in China, much has been tried and learned, and a great deal has changed, as we hope this book has shown. The wall of xenophobia that first greeted the disease was undermined by the discovery of domestic transmission among drug injectors and plasma sellers, but that in turn was quickly covered by the reluctance of the government at that time to acknowledge the problem lasting through much of the second decade of the epidemic. Now, in 2016, the picture looks very different indeed. China is open about its evolving HIV epidemic and is working actively and pragmatically to reduce the spread of the virus, including through the world's largest methadone programme for former drug injectors. The country also operates the world's largest HIV testing programme, performing some 144 million HIV tests in 2015, many of them in the groups most at risk of infection. It is this active testing programme that opened the door for another of the country's great achievements: the provision of care and antiretroviral therapy to hundreds of thousands of citizens, many of them living in rural areas. The rapid progress in providing treatment and care for those infected has been truly astonishing.

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9.1 Building Success Over 30 Years

In this short summary chapter, we try to distil the lessons of the past 30 years and to highlight the factors which have been critical to China's success. We also outline the challenges that remain and suggest some of the pathways for the future.

9.1.1 Listening, Trying and Measuring

One of the most important building blocks for China's success was the early experimental approach to HIV prevention in groups at high risk. With little domestic experience dealing with epidemics driven by sex or drug-taking, Chinese scientists and officials took every opportunity to learn from experience in other countries. Opening their minds to all possibilities, they read scientific papers and consulted with foreign colleagues and professionals (including professional sex workers). They travelled to observe different ways of doing things. And though they were not always comfortable with what they saw or heard, they were determined to try out proven approaches at home. Importantly, most of these early experiments fused intervention with research approaches, meaning that everything that was tried was rigorously documented. Over time, this small group of health officials and academics built up a very solid evidence base about what worked and what didn't in the Chinese situation. In the early years, there was only a limited opportunity to act on the results of these experiments. But the academics saw to it that information was carefully documented and, when possible published in credible academic publications, ready to draw on when the time was right.

9.1.2 "Best Practice" Is Not Always Best: Daring to Be Different

China learned a lot from international partners early in the epidemic. But local scientists and authorities were always careful to adapt what they learned to local conditions. China, with its vast population and strong, centralised government structures, is in many ways unique. China's HIV epidemic also developed in ways rarely seen in other countries. Significant outbreaks related to medical practices were recorded among orphans in Romania and in a handful of other places, but nothing like on the scale of the HIV outbreak among farmers who sold plasma in China's central provinces.

These unique characteristics arguably demanded (and also facilitated) a unique response, one which did not necessarily follow internationally accepted "best practice" at the time. Chinese health authorities took the initiative to try out these unique responses, sometimes in the face of opposition from both domestic and foreign constituencies. The most notable example of this was the decision in 2004 actively to seek out people who had sold plasma in the mid-1990s and to offer them HIV testing. The programme identified tens of thousands of people who needed HIV treatment and successfully linked a high proportion of them with the

healthcare services they needed. In some areas, social support for affected families and communities was also provided. Following the success of this programme, active testing strategies were expanded to other populations at high risk for HIV.

Another example of bold programming was the provision of methadone to drug users on a massive scale. Methadone programmes are promoted by HIV prevention specialists working with drug injectors in many countries, but they have met with staunch political resistance in some of the countries' most in need of them – the most notable example being Russia. Unlike those countries, China put the health of its citizens first; it now provides treatment for some 200,000 heroin users and has been rewarded with a steep drop in new HIV infections in this group.

9.1.3 Putting National Needs First

In the early years of the HIV epidemic in China, much of the response was supported by loans or grants that came from outside the country. In many other lower- and middle-income countries, this led to a somewhat chaotic situation in which foreign donors (and sometimes even implementing NGOs) set their own priorities, often determined by their own institutional interests.

China did things differently. From the very start, almost all projects were discussed together with Chinese health authorities and researchers; those domestic authorities had a strong voice in directing funding to areas that would produce the greatest learning and potentially the greatest impact for the country. In addition, as it built up its own funding streams and programmes expanded, China took the international community at its word and began to implement the principle of “Three Ones”, in which foreign-supported programmes and data collection were integrated into a nationally led framework that prioritised the needs of China's citizens, rather than the interests of different international agencies.

9.1.4 The Importance of Political Leadership

China's experience demonstrates very clearly indeed the importance of political leadership, not just at the highest level but also in areas most affected by this diverse epidemic. The response to HIV in China took off on a massive scale only after the country's highest leaders threw their weight behind prevention and care efforts. But even before that, significant successes had been achieved by enlightened and adventurous local administrators who witnessed the damage that AIDS was doing to individuals, families and communities in their area. These local officials encouraged experimentation which later provided the country's top leaders with evidence on which to base decisions that affected the nation as a whole.

9.1.5 A Dedicated Workforce

In the early years of the epidemic, HIV-related work was not popular. A few people chose the field out of personal conviction; many more were assigned the task simply because they were quite junior. One of them was Xi Chen, now a Deputy Director of Hunan provinces CDC, who was sent to work on AIDS as a new graduate, way back in the late 1980s. “AIDS was called plague of the century and super cancer so nobody wanted to do this work”, he said. “Even I felt uneasy about it”. Chen has been doing HIV-related work ever since. Many of the “AIDS Warriors” who took a personal interest in HIV at the start of the epidemic have stayed in this sector for their whole careers. This kind of experience and institutional memory is extraordinarily rare in public health services, especially in lower- and middle-income countries. It has built continuity and progressive learning into China’s response, where in other settings people sometimes repeat past errors because nobody remembers that something has already been tried and found not to work.

The Chinese system has another advantage: the people who are active in health research are often also making decisions about service provision, and many go on to become senior policymakers themselves. This means that people who are best placed to learn from operations research and are most familiar with the situation on the ground are also in a position to take decisions that are based on strong evidence.

9.2 Challenges

As we’ve seen in the preceding chapters, China has fought many successful battles against HIV over the last three decades, but the war is by no means over. The country continues to face a number of challenges, some old and others new.

9.2.1 Enduring Stigma: Silence Is Deadly

Perhaps most intractable of the remaining challenges is the discrimination suffered by people living with HIV in China. The very government which passes laws to protect the rights of people with HIV continues to deny them employment. The very health authorities that have done so much to expand treatment for people with HIV also preside over a health service which turns infected people away from hospitals and refuses them surgery. Though the country’s most senior leaders have tried to show their support for affected communities, their commitment often does not trickle down to other levels of government or society.

The stigma that seems to hang like a great cloud over the HIV-infected in China stands in the way of normalising the infection, of treating it like any other manageable, chronic condition. It also dissuades people from discussing their own infection, including with their own families and sex partners. With testing on the rise,

more people than ever before know their own HIV status. But many continue to have unprotected sex, simply to avoid disclosing their own infection.

Some believe that the state should respond by criminalising this behaviour. Certainly, people who know they are infected should be supported in taking responsibility for their own actions and for the safety of their partners. However, experience in other countries suggests that criminalisation does very little to interrupt HIV transmission. Rather, it entrenches the very stigma that discourages open discussion and disclosure of HIV infection while making contact tracing virtually impossible.

It is not just the virus itself that is stigmatised in China; it is the behaviours that spread it. Though sex is fundamental to human existence, many Chinese citizens would rather not discuss it openly. Parents and schools remain very resistant to the idea that young people should be taught about the mechanics of reproduction, let alone about wider topics such as sexuality. Taboos breed ignorance, ignorance breeds fear, fear breeds stigma and stigma breeds active discrimination. Young people, for their part, want to know about the changes their bodies are undergoing, about relationships, about love. Many Chinese teenagers turn to their peers or to the Internet for information about these things; both sources are as likely to provide misinformation as to foster understanding.

9.2.2 A Changing Epidemic: Gay Men, Sexual Transmission

As other routes of HIV transmission are controlled, the importance of male–male sex in spreading the virus in China becomes more evident. This population presents very different challenges compared with those most affected earlier in the epidemic. Ending transmission to plasma sellers was relatively easy; it just required proper oversight of blood collection practices. Eliminating HIV transmission among drug injectors is also not too hard. Injectors do not generally want to share needles – they do so because they do not have easy, affordable and safe access to sterile equipment. Where that’s provided, it will be used. Injectors who hope to overcome their addiction will also welcome substitute drugs such as methadone that they can take orally. Prevention interventions are also generally appreciated by women and men who sell sex. For them, the primary concern is not the distant prospect of HIV, but rather the far more immediate danger of other sexually transmitted infections (STIs). These interrupt work and put a dent in income, much better to use a condom than to lose money. If they do get infected, they want to get treated and back to work quickly, so the STI treatment services that also reduce the risk of HIV transmission are popular too. Clients are also often concerned about STIs and are thus generally willing to use condoms.

In short, whether or not plasma sellers, drug injectors, sex workers and their clients have any interest in preventing HIV, they are largely happy to use the services that reduce their risk of infection.

The same is simply not true of gay men, nor indeed of the non-commercial heterosexual couples who are also an increasingly large part of the epidemic in

China. In intimate relations, most people value the appearance of trust more highly than disease prevention, so it is far harder to persuade lovers to use condoms than it is to persuade sex workers and their clients. Channels of communication differ, too. Their behaviour may be frowned upon in some circles, but it is not illegal. They cannot be reached, as drug users and sex workers can be, through public security services or in rehabilitation settings. In the cities, this new generation of socially networked young people intent on individual expression is not particularly interested in listening to the injunctions of political leaders or in dancing to the tunes called by health officials.

9.2.3 A Socially Embedded Approach

China has done a remarkable job of ramping up its health services to provide HIV testing and treatment services. Clinical prevention services, including methadone for drug injectors and antiretrovirals to prevent the transmission of HIV from pregnant women to their newborns, are now provided on a significant scale nationwide. For over 5 years, the 110,000 couples with one positive and one negative partner have also now had access to immediate treatment to reduce transmission within marriages. The further increase of testing and treatment among those at high risk may reduce onward transmission of HIV even more in the immediate future. But as Chap. 7 described, limited progress has been made in addressing the social, economic and cultural factors that shape behaviour and that put people at risk for HIV. Political and economic pressures to limit family size together with very strong cultural pressure to have a son have combined, for example, to create an imbalance in the sex ratio among people who are now coming of age sexually. It is not known whether that has contributed to the evident rise in same-sex relations between young men in China's cities, but it is perfectly plausible. What is clear is that these social drivers of risk are very deeply embedded and lie beyond the reach of health authorities. Addressing them will require commitment, effort and activity far beyond the nation's hospitals and health centres. These efforts will need to be resourced; as an increasing proportion of the HIV-specific budget is used up by treatment, it will be important to protect funding for programmes that prevent HIV both directly and indirectly, especially in the populations at highest risk.

9.3 Adapting for the Future

China has a history of reacting pragmatically to overcome the hurdles to well-being thrown up by the HIV epidemic, particularly over the last decade. The strengths that allowed it to do this well have not disappeared. Addressing the challenges listed above will, however, require using those strengths in different ways.

9.3.1 Community Engagement in the Response

A changing epidemic, driven now by behaviours that are themselves shaped by a rapidly changing society, will require a new engagement by affected communities and by society as a whole. This is not just about increasing access to individuals so that they can be tested for HIV and treated if necessary. It is not just about going around karaoke bars handing out leaflets and condoms. It is about encouraging communities to define their roles and take responsibility for their own well-being and destiny. Safe behaviours cannot be imposed by authorities; ultimately new community norms must be developed by the people who will adhere to them. As China HIV/AIDS Information Network's Lingping Cai says: "No one can control the development of society, you can't control the people's sex or desire to have sex, you can't control technology. But NGOs have the flexibility to help people to protect themselves in the way that people favour".

Experience in other countries suggests that it is possible, indeed even likely, that communities will come up with approaches to HIV prevention that differ from those promoted by health departments. Indeed, they may initially come up with approaches which don't directly address the virus at all, by working first to reduce discrimination based on sexual preference or to promote healthier lifestyles, for example. These may be the things that drive the social changes needed to support safer sexual behaviour in the medium term. They won't be achieved just by subcontracting community groups to deliver existing services to a larger number of people. They require genuine partnerships, and that implies a more equitable balance of influence in deciding what the priorities for action must be. As the WHO's Bernhard Schwartländer said: "The funds are there for NGOs, and that's a huge step forward. What's missing right now is a platform through which NGOs can actually participate in decision-making".

Supporting community development is a relatively new experience for the Chinese authorities, and the habit will not become entrenched overnight. The Chinese government, in common with almost every other government in the world, is wary of working with community groups in part because they aren't sure how to hold them accountable. That's especially a challenge at a time when the government is putting a strong emphasis on ensuring that public money is well spent and that taxpayer-supported initiatives deliver results. Accountability is also important to the people whom community organisations claim to represent. Non-government groups, for their part, often don't have the experience necessary to follow the complex accounting procedures demanded of them, and many are not used to thinking about how the impact of their work can be measured. CDC's officers can help them in this task by sharing data and information about the local epidemic, but a culture of information exchange is not yet well established.

There is no doubt that communities will have to step up and take more responsibility for their own health and welfare if the current wave of HIV infection is to be overcome. This is especially true of gay men, both young and old, but experience from other countries suggests that when sex workers and drug injectors come

together, they can also greatly improve their own welfare. Both groups are currently massively underserved by China's nascent non-government sector.

It is clear that authorities at the local, provincial and central levels want to control the HIV epidemic; it's also clear that where that control involves changes in community norms around something as intimate as sex, they need to work in partnership with those most affected. The existing fund to support community groups will, for the first time, allow salaries to be paid, which means that people will be able to earn a decent living by supporting their communities. This will contribute to the professionalisation of community organisations. As experience with using these funding channels grows and government and non-government groups grow more comfortable working together, trust will develop, genuine partnerships will be more likely to flourish and HIV prevention efforts more likely to succeed.

9.3.2 Breaking the Silence

The Chinese leadership has made its commitment to support those living with HIV very clear indeed. However, the enduring discrimination against people living with HIV in China will continue unless health service providers and government employees at all levels of society share that commitment. China has done well to create a supporting legal framework for people with HIV, but without enforcement, the laws have no value. China has made a huge financial and logistical commitment to provide treatment to prolong the lives of people with HIV, only to allow them to be continually robbed of their dignity. To meet the commitments it has made in international forums, as well as the pledges that China's senior leaders have made to the people they govern, officials at all levels will have to turn their attention and energy to enforce anti-discrimination laws and to sanction those who violate them.

Discrimination is fed by stigma, and the stigma surrounding HIV continues to be fed by statements and campaigns that demonise the behaviours that spread the virus. This simply entrenches negative attitudes towards people who are infected. But it doesn't seem to have much effect on risk behaviours themselves. There's no indication that Chinese citizens are losing their appetite for commercial sex, and behavioural surveillance suggests that both extramarital sex and sex between men are on the rise. These societal changes follow a pattern also seen recently in many other Asian countries. However, they are rarely talked about, and young people are left without reliable information about sex and sexuality.

China's ministry of education has now recognised this gap in information, which has contributed to a steep rise in HIV infections among (mostly male) college students across China. But at the local level, educators sometimes react to the issue of increasing sexual expression among young people simply by denying it. In an effort to undermine this denial, local health departments have now been tasked with keeping education authorities up to date with what's really going on in their local epidemics. No concrete steps have yet been taken to increase sex education in primary or secondary schools. But in a programme backed by the nation's First

Lady, Peng Liyuan, college students in some 40 universities nationwide are now being supported to discuss HIV with their peers, to answer questions about the virus and to offer HIV tests.

9.3.3 90-90-90

New initiatives do not imply that past successes should be abandoned. Though it's evident that China needs to expand its approach to HIV beyond the biomedical, it will continue to strive to ensure that people with HIV get the treatment they need. China was among the very first countries to formally adopt the "90-90-90" targets set by UNAIDS in 2014: 90% of infected people should know their status, 90% of diagnosed cases should receive antiretroviral medication and for 90% of those on therapy, the virus should fall to levels undetectable using standards tests [1].

These numerical targets are intended merely as calls to action. They are all dependent on the estimated number of people living with HIV, which, as we saw in Chap. 5, is in itself an imprecise number. China's efforts are driven less by a numerical target than by a commitment to reach as many people as possible with testing and treatment services. China's current official estimates indicate that close to 70% of those infected have been diagnosed. Some people who think they may be at risk are probably reluctant to test because they don't believe results will be kept confidential. To overcome this barrier, China will promote the use of self-testing. More service provision by community-based groups who have the freedom to work with greater independence from the health authorities is also likely to improve customer-centred service, encouraging those who test positive in home testing to seek care.

Two recent policy changes will contribute greatly to increasing the proportion of diagnosed people who take medicine to control the virus. The first is a decision, announced in June 2016, to drop any biological thresholds for treatment. Until then, people had to get tested to see whether their CD4 blood cell count was below 500 per millilitre before they could be treated. Though the "one-stop shop" services reduced dropout, some continued to slip out of the health services at this point, and the threshold itself reduced the proportion of those diagnosed who were eligible for treatment to just 78%. The second change that should boost treatment numbers is a long-awaited commitment to provide new medicines, including combination pills which make it far easier for people to take their medicines as they should. The limited range of medicines available and the failure to switch to newer formulations with fewer side effects have contributed to slow uptake of antiretroviral therapy in China. Newer, easier-to-take drugs should encourage more newly diagnosed people to embrace the opportunity offered by treatment, especially if they can easily get hold of those drugs wherever they are in the country. Wider access to more convenient drugs will help people to take their medications more consistently, while a wider variety will provide more options for rapid switching if people develop side effects or if the virus becomes resistant to the drugs they are taking. Both of these things will improve viral suppression, contributing to progress

towards the third target. The drive to ensure that targets are met will require more regular monitoring of viral loads, which will have an important benefit for clients because it helps doctors to spot potential treatment failure sooner.

9.4 The Journey Continues

HIV has taught China a lot over the last 30 years. It reminded the nation that it was not isolated from the world and that physical borders are not effective barriers to virus nor indeed to technological and social changes. The fate of tens of thousands of people who sold their plasma and became infected with HIV underlined the serious human consequences that sometimes accompany the headlong rush for economic growth. Denial was shown to be not only useless but also damaging. The power of real political commitment to drive effective change, on the other hand, has been demonstrated very clearly.

Many lessons are equally valuable for other countries, too. The importance of understanding the specific features of local HIV epidemics and of building up a strong evidence base have been underlined by China's experience. A willingness to take risks, to seek pragmatic solutions and to adapt to changing circumstances has been the bedrock of the nation's success.

As long as that pragmatism and flexibility continue to underpin the response to HIV, China's government and its citizens will be in a strong position to face the next decade with confidence, knowing that they will be able to work together to limit the number of new infections and to improve the well-being of people who live with HIV.

Reference

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