

A Qualitative Exploration of the Role of Antiretroviral Therapy on Chinese Rural Life*

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Abstract

Objective To explore factors influencing the quality of life of people living with HIV/AIDS (PLHA) and receiving antiretroviral therapy (ART) in rural China.

Methods In-depth interviews with 20 PLHA were conducted in March 1999. Participants were recruited from the USAID-funded Longitudinal Enhanced Evaluation of ART Project, which tracks a cohort of eligible PLHA receiving treatment at five collaborating treatment centers in Guangxi Autonomous Region, China. An interview guide (semi-structured with open-ended questions) was developed to provide a qualitative examination of the quality of life of PLHA.

Results Participants identified that ART affects physical health, including the experience of pain, side effects, and opportunistic infections. ART imposes lifestyle constraints such as reduced mobility due to drug procurement, and social restrictions due to the daily drug regimen. Participants discussed the psychological burden of taking drugs, and the fear of accidental transmission to others, or having their disease status known by others, as well as optimistic feelings about their future due to ART. ART poses a significant drain on individual's economic resources due to related medical costs, and inability to seek seasonal migrant labor due to reduced mobility.

Conclusion While China's national free ART program improved the physical health of those surveyed, their social and economic needs were left unaddressed. To improve life outcomes for PLHA, and by extension, the wider Chinese population, quality of life measures should be included when evaluating the success of the ART program.

Key words: HIV/AIDS; ART; Quality of life; Qualitative study; China

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INTRODUCTION

The Chinese Ministry of Health reported in 2009 that since the first identified human immunodeficiency virus (HIV) case in 1985,

there have been a further 319 877 incident cases of HIV infection reported in China. The Joint Assessment Report, a collaborative report written by the Chinese State Council AIDS Working Committee, UNAIDS, and the World Health Organization (WHO),

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reported that in 2009 an estimated 740 000 people were living with HIV/AIDS (PLHA) in China, including 105 000 AIDS patients^[1]. Experts consider sexual transmission to be the dominant mode of HIV transmission in China^[2].

In December 2003, the Chinese government initiated the "Four Frees and One Care" policy to provide, among other things, free antiretroviral treatment (ART) to residents with HIV living in urban poor communities and rural areas. Based on the success of pilot programs started in 2004, the government scaled up national treatment programs and by 2006 the "AIDS Prevention and Treatment Act"^[3] and the "China AIDS Containment and Prevention Action Plan (2006-10)"^[4] established ART as a central pillar of the county's AIDS control policy. By the end of 2009, there were 65 481 individuals receiving ART, accounting for 62.4% of the total estimated number of AIDS patients alive at the end of 2009^[5].

China's free ART program has achieved impressive coverage and reach even by developed world standards. However, with the lives saved comes the added challenge of ensuring a viable and dignified life for those living on ART. Quality of life studies^[6] of PLHA after the initiation of ART provide a composite measure of the diverse aspects of an individual's health, including physical, psychological, and social wellbeing. However most of this research is set in the urban environments of the developed world and has little applicability for PLHA in China, the majority of whom are rural residents of low income status^[7]. In addition there are no qualitative data available regarding the effects of ART on PLHA's quality of life in China. To address this, our study explores the unique challenges affecting PLHA in an agricultural region of southern China. We aim to translate their concerns and experiences into recommendations for treatment and care programs that better address the needs of PLHA.

EXISTING RESEARCH ON PLHA'S QUALITY OF LIFE

Quality of life is defined by the WHO as "the individual's perception of his/her position in life in the context of the culture and value system in which he/she lives and in relation to his/her goals, expectations, standards and concerns"^[8-9]. This concept incorporates physiological, mental, cultural and social aspects of an individual's life into a comprehensive score that can be compared across individuals living in various cultures and value systems. Six major domains make up the quality of

life composite score for people living with HIV, consisting of measures in the following areas: physical health, psychological health, level of independence, social relationships, environment, and spirituality/religion/personal beliefs.

People living with HIV/AIDS, particularly in the developing world, face a unique set of challenges that complicate the assessment of quality of life. In many parts of the world, HIV/AIDS disproportionately affects poor and marginalized populations, making quality of life highly sensitive to factors such as poverty and lack of education^[10]. Physical health is of primary importance in developing economies where many individuals rely on manual labor for their livelihood, making physical health outcomes a fundamental factor impacting the quality of life of PLHA in poorer parts of China. In addition, the high cost of treatment and care for PLHA presents an added strain in the most heavily impacted regions of China, where medical resources are scarce and PLHA can rarely afford medical care even in the absence of HIV. Finally, the fraying of family and social relations due to shame associated with having an HIV infected friend or relative can be highly destabilizing for PLHA in China, where highly structured social networks are a primary means of social and economic support^[11-12].

Existing studies of quality of life among PLHA in China have explored a wide range of factors affecting quality of life including social stigma, social support, AIDS-related symptoms, and psychological status^[11-15]. Others have evaluated care and treatment interventions on quality of life^[16-17]. However there is little research on the role of ART on quality of life, with the exception of studies by Wang et al. (2008)^[18] and Zhao et al. (2008)^[19], which focused on the short term impacts of ART adherence on quality of life. Therefore, this study investigates the role of ART on the lives of rural Chinese residents in Guangxi province, a poorer region of China that has been heavily impacted by the HIV epidemic. By providing a better understanding of the psychological and behavioral context for quality of life among PLHA receiving treatment, this paper seeks to understand what quality of life means to them, and provide recommendations for tailored care and support programs.

METHODS

Study Participants

This study was approved by the Protection of

Human Subjects Committee of Family Health International, USA, and the Guangxi Institutional Board.

Participants ($n=20$) were recruited from the USAID-funded Longitudinal Enhanced Evaluation of ART Project, which tracks a cohort of eligible PLHA receiving treatment at one of five collaborating treatment centers in Guangxi Autonomous Region. Purposive sampling was used to include a diverse range of participants in terms of age, sex, occupation, and quality of life scores.

Research Methods

In order to understand what quality of life means to PLHA receiving ART in rural China, the study team conducted single interviews with 20 PLHA. A short interview guide (semi-structured with open-ended questions) was developed by the study team, and revised following content analysis to reflect local situations. The semi-structured design provided opportunities for the interviewers to probe further into topics about which the interviewee had particular insights or opinions. The topic guide allowed flexibility to focus on specific concerns or suggestions on how treatment programs could better improve quality of life.

After providing voluntary and informed written consent, each participant was asked 10 questions assessing socio-demographic information such as age, gender, and education level. Prior to questions specific to quality of life, definitions of key interview terms were given to promote respondent understanding of interview terminology. Interviews were conducted in a private hospital room. Interviews were approximately one hour long, and hand written notes were later transcribed into digital format.

Content analysis involved coding text in order to identify common themes pertaining to quality of life factors and changes experienced after the initiation of ART. A preliminary codebook containing key concepts and categories was developed upon initial content analysis.

RESULTS

The average age of the participants was 35 years, and most were male ($n=14$), married or cohabitating with a regular partner ($n=15$), and worked as seasonal migrant laborers ($n=14$). The average duration of ART for participants was 1.78 years. The most likely route of HIV infection reported was heterosexual intercourse ($n=15$) with the remainder reporting injection use of heroin ($n=3$), transmission

route unknown ($n=1$), or male-male sex transmission ($n=1$). Most interviewees learned ($n=13$) of their HIV positive status when they presented at a medical center for AIDS related symptoms and underwent physician recommended testing.

Freedom from Physical Pain

Eight out of 20 informants said that they had suffered physical symptoms in the 6 months prior to receiving ART. As expected, the most commonly reported positive quality of life change after receiving ART was improved physical health. Many interviewees confirmed the findings from other quality of life research^[20], which shows that patients receiving ART often feel physically healthier than they did prior to starting treatment.

Before the treatment I was so skinny. ...Then I was introduced by my aunt to Pingxiang. My wife knew my HIV status and stayed at the hospital to take care of me. She also had a HIV test. She was negative... I feel quite good following the ARV [antiretroviral] treatment. It seems that I am totally recovered. I haven't felt bad since starting the treatment in 2007. I use condoms with my wife. I really do not want to transmit HIV to her, as she is so kind and supportive. [Male, 37, farmer]

I'm feeling a lot better now. Before receiving the therapy, I frequently suffered from diarrhea, vomiting and could not eat anything. But now I'm better and it seems that I will regain a normal life. [Female, 21, Farmer]

I'm in good spirits after starting treatment, and my body feels much better. With great support from my parents and husband, I am gaining weight and am now 53.5 kg as compared to my previous 39 kg. I also don't feel as tired as before. [Female, 36, Seasonal migrant worker]

There are good effects and I generally feel much better after starting treatment; it seems as though I have almost recovered now. I haven't suffered any uncomfortable side effects since starting treatment two years ago. [Male, 36, Farmer]

Constraints of ART on Lifestyle

Despite the immediate positive changes on physical health, many PLHA described numerous constraints that the initiation of ART had on their personal lifestyles. China's national free treatment program currently requires patients to receive their medication from a designated treatment center in the same city in which they hold permanent residence. This compromises their ability to leave

home for extended periods of time, placing significant economic constraints on many rural PLHA who work as migrant laborers during the off season. Several of those interviewed pointed out that returning home for antiretroviral drugs (ARV) drugs results in extra travel costs.

I can't go outside to find a job because I have to come back home every three months to get treatment...I have run out of money...My father pays no attention to me. So I just come back home to get the free medicine. I cannot go out to earn a living, and, I have contracted my farmland to others for just 400 yuan a year. [Male, 27, Farmer]

I used to work in Guangdong during the off season. However, because it is inconvenient for me to come back every three months to fetch the medicine, I've decided to stay at home [since beginning treatment]. [Male, 25, Unemployed]

I have to do monthly physical check-ups because I've changed my drug regimen. They require frequent travel that affects my work and also costs a lot of money. I cannot afford it...I hope we can get our medicine more readily because it takes a long time to pick it up back at home. It always takes a whole day on travel. And it usually takes me 3 to 4 hours to get the medicine. [Male, 36, Unemployed]

Another commonly reported constraint was the time-consuming and highly regimented life style that daily ART regimens demand. Some found the regular timing of drug administration to be too strict, while others felt obliged to stay near their homes in order to take their drugs on time, particularly if they were hiding their condition from others.

I must go back home to take my medicine whenever I am out with friends. It is annoying. If we're not far from my place I can go home for the medication. If the place is far from home I bring the drugs with me, but it might be difficult to get water there. I miss doses once every three months or so. It is really inconvenient to go out with friends if I have to remember to take my medicine on time. [Female, 22, Seasonal migrant worker]

Another nuisance is that I must get up at 8 o'clock to take medicine. I used to go to bed around 2am after a day's work – I was a manager for an entertainment club for senior citizens, mostly for mahjong. [Male, 45, Small business owner]

In addition to restrictions on mobility and time, a common theme described by most informants was how the physical side effects of ART impacted their ability to regain normality in their lives. In particular, interviewees mentioned their altered appearance

following ART initiation, a common side effect given the metabolic complications of ART and changes in body shape. Decreased sex drive was also cited as a factor impacting PLHA's freedom to live a normal life.

I used to have sex once or twice a month before receiving therapy, but now I have less sexual desire, and have it only once every 3 to 4 months. [Male, 33, Farmer]

The side effects of medicine are quite awful. My face has become very skinny since starting medication and I've had a lot of adverse side effects. Many friends and relatives often ask me why I've become so skinny and I think they talk about me a lot which makes me very uncomfortable. [Female, 33, Wholesaler]

Finally, many of the respondents described the burden of medical costs associated with the initiation of treatment. Although the Chinese government has provided free ART for urban poor and rural PLHA since 2003, the individual must still cover treatment for other medical costs associated with the disease, including medical examinations, diagnostic tests, and opportunistic infections. Though without treatment, disease progression will naturally increase medical needs, patients receiving treatment must take part in regularly scheduled tests and checkups, and frequently consult with physicians regarding treatment outcomes and side effects, all resulting in higher medical costs. Since many rural residents in China do not have health insurance, these additional services represent a significant economic burden.

If all the medical examinations and treatments were free of charge, we would feel much less worried. But now we can't find a job so we don't have any money to pay for things. [Male, 37, Unemployed]

I worry about having enough money so that when the disease progresses I'll be able to afford the medical costs. Then I would feel more at ease and wouldn't have as much pressure, and I'd even be able to support my family. However I'm dependent right now on my parents help me to cover the treatment. They are old and tired though, and I don't want to trouble them any longer. [Female, 21, Farmer]

By increasing the frequency of interaction with hospitals and doctors, ART has provided HIV/AIDS patients with improved medical treatment, but at a personal economic cost.

The most immediate effects of ART on the lives of PLHA were expressed as comparisons between informants' lives before and after ART, with

normality being the standard by which they evaluated their quality of life. The most important qualities of a normal life as cited by the respondents were mobility, time, normal appearance and sex life, and freedom from medical costs.

Psychological Effects of ART

Many respondents experienced conflicting emotions about the role that ART played in their lives. Some described it as a life saver while other felt it was a life sentence to daily drug taking. To a few, ARV drugs represented a burden to bear for the rest of their lives.

My biggest wish is to have my disease cured completely, although I know this isn't possible and I have to take medicine all my life. [Male, 36, Farmer]

Because the doctor said I have only 5 to 6 years to live, I have no hope and don't want to do anything... I'm so troubled that sometimes I don't want to take the medicine. It tastes so bad. It's hard for me to persist in taking medication...but I'm trying to take it a day at a time because I know there is no cure. [Male, 33, Farmer]

I don't want to tell any of my friends. I am afraid they will worry that I will die. I do not want to lose my friends, rather than lose my life. [Male, 36, Farmer]

Some PLHA expressed a fear of having others find out about their disease status because of the daily, permanent, and time-specific nature of the ART drug regimen. They feared it would create more opportunities for family and acquaintances to discover their disease, which added to the stress of many PLHA on ART.

Now I'm living with my mother and brother—my father died—and neither know I've got AIDS. I spend my own money for treatment....I don't want them to know I'm taking medicine [Male, 35, Farmer]

Sometimes I want to end my life because I must hide the medicine and take it in secret. It's really very stressful. [Female, 33, Wholesaler]

Others, however, felt optimistic about their future and felt that the drugs prolonged and therefore improved their lives.

I'm in a better state of mind than before because I have hope after receiving treatment. If I hadn't received treatment, I would have no hope. [Female, 33, Wholesaler]

The disease calls for medication all my life. The government provides us with free medicine, so I have nothing to worry about...I've never thought about death. I have nothing to worry about because I have

doctors and the government, our country will provide us with free medicine to prolong our lives. [Male, 62, Retired]

The medicines are free now as the government has pledged, and our country will spend a lot more money on us, so we currently have no great worries. I am careful about taking my medicines twice a day...I'm optimistic and enjoying fishing with my friends. [Male, 33, Small business owner]

As long as I could remain happy every day as I am now, I'll be satisfied. Now I feel more relaxed and don't fear the disease at all. I'm feeling better because I have taken medicine for 2 years which has maintained my condition. [Male, 45, Farmer]

Interestingly, positive outlooks were often linked to a faith in the government to provide for PLHA by providing free ART. The positive views expressed by two respondents in particular were also notable for their advanced age. In contrast to past literature on the quality of life of PLHA that has found an association between older age and a reduced quality of life^[21-22], these respondents said their older age made it easier for them to accept their lives on treatment. The rationale was that they were better suited to a life on ART since their life savings and government pensions eased immediate economic pressures and because as seniors they were already accustomed to regularly taking drugs.

No one knows that I have AIDS and I'm always optimistic because I'm over 60 years old and have nothing to worry about; only to insist on treatment. [Male, 62, Retired]

I'm 64 years old...it is not difficult for me to take medicine every day. I am used to it. There are no side effects and I have never missed a dose. I take the medicine at nine o'clock every morning and night. ...I need no help at present. Having several thousand yuan of pensions each month, we [my wife and I] have no difficulties in supporting ourselves... there is no great impact on my family from getting AIDS because we are getting older and we don't fear the disease... I like to write poetry, novels, memoirs, etc. [Male, 64, Retired]

Persisting Concerns

Despite receiving ART, respondents described many persisting concerns over the course of the interviews. This feedback highlights other important concerns of PLHA that have great sway over the quality of the lives extended by China's free ART program. A better understanding of these concerns can directly inform the design and evaluation of care and treatment programs.

One of the greatest sources of stress was related to the welfare of PLHA's own families. Many expressed concern about how to provide for their elderly parents and children given their already strained economic situation.

Mainly because I can no longer work, I need support to put my child through school until he reaches 18. I also worry that there will be no one to take care of my father, having an income resource is so important...if I didn't need to take care of them [my father and son], my quality of life would be much better. [Male, 33, Farmer]

I'm living under exhausting pressure. My children now study in Guigang. My son needs more than 1 000 yuan every semester and my daughter needs 960 yuan. I have great economic pressures ... I have no wishes except that my children could graduate from college one day. [Female, 36, Seasonal migrant worker]

If I had enough money, I could think of raising a child and leave the child my money after I die. Never before have I had such a strong wish for financial security like I have now. [Female, 21, Farmer]

Another source of stress for PLHA concerning their families was the fear of accidental transmission of the virus to their loved ones. This fear originated both out of inadequate understanding about the prevention of secondary transmission, as well as out of the pressure to have children.

My husband and I never used condoms before getting infected with HIV. Now [that I am infected] I insist on him wearing one when we have sex, but he doesn't like it...and if we do use one I still fear that it might break during intercourse. [Female, 44, Farmer]

We wish for more knowledge about routes of HIV transmission so that we can know whether or not we can safely embrace our children. [Male, 33, Small business owner]

I heard that there is a way to prevent us transmitting HIV to others. Every time I eat with my friend or sleep in one bed with my female friend, or chat, or have food together, I always worry that I will transmit HIV to them. [Female, 26, Cashier]

Finally, unintended disclosure of their disease status was a persistent concern for many of the PLHA interviewed. Some felt that they could not trust their healthcare providers to conceal their disease status, and many did not trust the healthcare system to be able to effectively maintain patient privacy.

I hope that my HIV status will not be disclosed by health workers, otherwise I will have a hard time. I have never participated in any HIV positive group

activities. I worry about being known by others in the activities. That would be too bad for me. [Male, 37, farmer]

We especially want the hospital to keep our information secret. They used to record all the patients' names at the doctor's office and everyone could see them but now the practice has been rescinded. I don't think it's a good idea for HIV/AIDS infected people to congregate at the hospital or anywhere else; it's just not a good idea since it might attract attention and expose our infection status to outsiders. [Male, 33, Small business owner]

DISCUSSION

This research focusing on the role of ART on the quality of PLHA's lives found that their post-ART life was deeply shaped by each individual's ability to regain normality in their daily lives. That is, while most respondents expressed positive feelings about the life saving effects of ART, their attitudes were often more an extension of their preexisting life circumstances than a completely new beginning. This was most evident in cases of economic hardship and their concerns about how to provide for loved ones.

These study findings have important implications for China's national free ART program. Indicators of program effectiveness have traditionally focused on treatment coverage, morbidity, mortality, and incidence of drug resistance. However the realization of ART's full potential for sustaining and improving the quality of life of PLHA is beneficial for the overall health of the population. A better understanding of the qualitative factors that shape the role of ART in the lives of PLHA—particularly in developing country settings—is therefore critical for not only achieving better health outcomes, but also for the prevention of secondary HIV transmission.

Policy and Program Recommendations

Several observations are of particular interest for their relevance to specific policy and program recommendations:

First, many informants discussed the challenges of having limited geographical access to free ARV drugs. Patients are only able to obtain treatment and drugs at the treatment center local to their registered hometown, and the rigidity of China's household registration system prevents patients from changing their residence status for medical reasons. As a result, many HIV/AIDS patients become rooted to their registered residence while

undergoing treatment, greatly limiting their freedom of movement and ability to pursue work away from home. This is a particular hardship for those who rely on seasonal migrant labor as their primary source of income. Based on this feedback, the authors recommend that China's treatment program establish a centrally managed medical records database and create policy and systems that allow all treatment centers to offer basic care and drug procurement to all PLHA in China.

Second, fear of accidental exposure of their disease status was a great source of concern for many of the interviewees. Stigma and discrimination are still quite persistent in many parts of China^[14, 23], potentially affecting not only emotional wellbeing of, but the economic opportunities for PLHA who may not be able to find work should potential employers learn of their disease status. Specifically, many PLHA were unable to comprehend how hospitals and clinics would be able to ensure patient privacy. We therefore recommend that treatment centers incorporate seminars and counseling sessions to inform patients of the principals and mechanisms of patient confidentiality systems used in modern healthcare systems. Such programs could also educate individuals on patient rights and improve the overall standards of transparency of Chinese healthcare establishments.

Third, the welfare of family members was a concern echoed through many of the interviews, particularly for those who were the main provider for their family. According to the data from a UNAIDS report in 2008, HIV cases in the 20 to 39 year old age group accounted for 70 percent of all cases^[24], which suggests that many Chinese PLHA are still of working age and therefore earn the main source of income for their families. Long term economic security is therefore of utmost importance for these individuals, particularly in light of their shortened life spans. China's weakened welfare safety net has left these groups particularly vulnerable, and in spite of the government's Four Frees One Care program, the specific social and economic needs of PLHA in this study were left unaddressed. Financial consultations, or applications to procure public funds for medical and school fees for families impacted by HIV should be considered.

Finally, clinical outcomes that improve the physical health of PLHA are particularly important for the majority of the infected population of China because most still rely on manual labor for their primary source of income. Currently, the spread of HIV infection among the mobile population has been

increasing rapidly in China, and in some provinces and cities more than two-thirds of HIV positive cases are working as seasonal migrant workers^[25]. Based on this, we recommend that treatment outcomes for PLHA focus not only laboratory results such as viral load or CD4 count, but also on other factors that affect physical health such as opportunistic infections and physical side effects. Current patient education programs and treatment of drug side effects and opportunistic infections should continue to be prioritized and enhanced. Quality of live measures should always be included when evaluating the success of the ART program.

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