

# **Education and Identity Construction for HIV-Positive Young People in China**

Yiyang Zhang\*

## **Abstract**

In the last ten years, HIV has become a treatable, even manageable, malady. However, due to social stigma and ignorance surrounding its spread, HIV-positive children and youth in China face significant challenges in enrolling and integrating into the educational system. Against the background, the impact of HIV on the life of a child is profound. Thus, the study investigated how being HIV-positive shapes the identity and sense of social belonging of young individuals in China. Following a qualitative research design, the study conducted in-depth semi-structured interviews with two HIV-positive young Chinese adults who completed their compulsory education at a special school for HIV-infected learners and were pursuing higher education. The participants' experiences in mainstream schools (including primary schools and universities) and exclusive education were analyzed, and their identity development was categorized into three phases: early life before attending the special school, experience at the special school, and life in higher education. The study findings revealed that experiences of parental loss and HIV-related stigma at a young age became the negative sides of the participants' identities, which affected their disclosure choices and intimate relationships in their twenties. However, their identity development also led to a stronger sense of social belonging. The exclusive education provided them with various and robust support, particularly psychological support, which enabled them to participate equally and confidently in subsequent mainstream universities and social activities, facilitating them in pursuing the meaning of life.

Keywords: HIV-positive young people, education, identity construction,  
social belonging, China

\* Department of Social Work and Social Administration, The University of Hong Kong (China)

## Introduction

The human immunodeficiency virus (HIV) /acquired immune deficiency syndrome (AIDS) in the last ten years has increasingly affected young groups. According to the latest 2022 data, approximately 14-15% of people living with HIV/AIDS (PLWHA) were young people aged 15-24 years in China, and 128,646 were unable to attend schools (Li & Zhang, 2023). Additionally, an estimated 8,000 children under 14 were HIV-positive (NHC press conference on November 23, 2018). Youth has been the group with a more accelerated upward trend of new cases and AIDS-related deaths than other cohorts (Zhang et al., 2017).

Because of social stigma and reduced tolerance of differences among people (Zukoski & Thorburn, 2009), HIV-positive (HIV+) young groups in China still face significant challenges in enrolling and integrating into the educational system. Although the State Council of China affirmed the legal entitlement of HIV/AIDS patients and their families to education in 2006 and concurrently introduced a 9-year compulsory free education policy and an inclusive education policy, the practical efficacy of these policies was hindered by two layers of social realities. At the national level, the studied groups tend to be overlooked due to their minor representation of the overall population. At the social level, repeated leakage of HIV+ learners' information increases their vulnerability to stigma and subsequent rejection. Findings of the China Stigma Index Report (UNAIDS, 2009) showed that teachers accounted for 36% of confidentiality breaches of HIV-infected individuals, followed by government officials at 35% and medical staff at 26%.

Therefore, guaranteeing the educational rights of HIV+ youth is a crucial and challenging endeavor. However, previous studies, in a Chinese context, mainly focus on medical and psychological conditions among the infected population (e.g., Zhou et al., 2019), and the educational rights and needs of HIV+ school learners remain unexplored. Thus, prioritizing attention and offering support to children and young people living with HIV/AIDS in China has become an imperative and crucial topic for discussion.

## Literature Review

### 1. Stigma and identity

Erving Goffman (1974) defines stigma as a trait that significantly discredits individuals and diminishes their social status. Additionally, individual behaviors cast a reflection on the larger family, even the whole community group, and can affect the reputation of every member involved (Yoshioka & Schustack, 2001). Thus, HIV stigmatization, which is culturally constituted, does not only direct against high-risk groups, but also abnormalizes all positive children and young people even without “dirty” behaviors.

This impact of stigma on an individual's identity formation can also be elucidated by Taylor's Politics of Recognition Theory (1994). He contends that an individual's original identity depends on recognition from the external world and significant others. To combat the demeaning and confining image mirrored back to the marginalized groups, society should help people shape their identities through open dialogue instead of a predetermined social script.

As a pivotal component in social activities, school experience is essential in developing an individual's self-reflection ability and forming their identity (Cole et al., 2005). However, according to Lannegr-Willems and Bosma (2006), research on identity formation within the school context still needs to be developed.

## **2. Children/youth-specific research of HIV-infected groups**

HIV/AIDS-related issues are often taboo in national and international discussions due to their sensitivity (Parker & Aggleton, 2003), resulting in limited research in the field. The findings of children/youth-specific studies of HIV-infected groups mainly involve the following two aspects.

### **2.1. Well-being, quality of life, and social support on seropositive youth**

In their investigation, Petersen et al. (2010) identified the principal psycho-social hurdles encountered by PLWHA, particularly among adolescents. These challenges encompassed the loss of biological parents, struggles with identity formation arising from their HIV+ status, and the complexities associated with disclosing their condition due to external stigma and discrimination. Moreover, prior research demonstrated that depression in HIV+ children is likely to result in maladaptive behaviors such as school dropout, alcohol and drug use and engaging in high-risk sexual behaviors, which can have negative impacts on their quality of life and a profoundly harmful influence on society (Sherr et al., 2011).

In 2019, Zhou and colleagues revealed a depression rate of 32.41% among 145 HIV+ children aged 8-18 years old in China. They also suggested that high levels of perceived social support could enhance self-esteem, confidence, and efficacy, ultimately reducing depression levels.

In the field of academic research, Chinese-infected children and young people still have not received sufficient attention. Few studies have examined the impact of an unfriendly educational and societal environment on their growth and development. This absence is likely due to the limited availability of youth-specific HIV data in China (AIDSinfo, 2023).

## 2.2 Studies on education for HIV-infected children

International and Chinese evidence has indicated several educational challenges for HIV+ learners involving financial burdens, inequitable resources and stigmatization, and suggestions have been proposed (Iliyasu et al., 2020). However, insufficient efforts have been made in schools and society. For example, in their research, Robson and Kanyanta (2007) emphasized that targeted inclusion development in Zambia could not thrive due to a lack of proactive educational policies and practices. Mitchell et al. (2007) also noted that some educators lacked the necessary resources and skills to ensure quality education. Moreover, Watkins et al. (2014) argued that compared to inclusive education, special education could provide more specific support, such as intervention programs for HIV-infected youth, and potentially avoid complex risk factors that can lead to additional obstacles to education and traumatic experiences, such as household migration, crisis fostering, poverty, and changing schools frequently.

These discussions stress a significant dilemma: the advantages of inclusive education cannot entirely solve the issues raised by exclusive education, and scholars supporting exclusive education, such as Watkins et al., have not provided detailed guidelines on mitigating the adverse effects of studying in a segregated environment. Therefore, more evidence from empirical studies is urgently required.

## Methods

### 1. Sample

Given the difficulties of recruiting Chinese HIV-infected young people, a convenience sampling method was used (Bryman, 2016). Two HIV-positive participants (one 22-year-old male anonymous as “Xiaozhi” and one 23-year-old female anonymous as “Xiaohua”) were selected. Both informants disclosed that their HIV infection was acquired through mother-to-child transmission and had been diagnosed for 16.5 years on average. They were graduates from the only special school for HIV+ learners in China, pseudonymously named Green School in this study. They were pursuing higher education when the investigation was conducted.

### 2. Data collection

To comprehend how education and social recognition shape the identities of HIV+ young individuals and impact their social engagement, a qualitative research approach utilizing semi-structured, in-depth interviews was employed.

The interviews were held in Chinese separately via Skype. Xiaozhi’s interviews consisted of two sessions, each lasting around one and a half hours. The interviews with

Xiaohua were conducted over three sessions and lasted five hours in total. Before the data analysis, each interview was tape-recorded, transcribed, and translated for analysis.

### **3. Data analysis**

Thematic analysis is used in this study. Following the research questions, the relevant descriptions of a phenomenon from the interviews were compiled and organized under specific themes (Daly et al., 1997). Narrative analysis was also applied to identify and analyze the extent to which participants' stories and feelings provide insights into their lived experiences (Sandelowski, 1994).

### **4. Ethics**

Given the sensitivity of the topic, it is imperative for me to uphold the principles of respect, integrity, and amicability. Each participant received an information letter outlining the study and the confidentiality arrangements, with a consent form to be returned to the researcher and a copy for their records. All respondents were informed that they had the right to withdraw consent to participate at any time before the data analysis unconditionally. Confidentiality was assured to all participants.

## **Findings and Discussion**

In this study, both participants experienced three phases in their educational journey: studying at the inclusive primary schools before the Green School, residential life at the Green School, and campus life at the mainstream universities. Their identities were constructed during the process through interactions with teachers, peers, communities, and themselves.

### **Phase 1: The formation of stigmatized identity at a young age**

Both of the participants considered the period before they went to the Green School as the most isolated environment, as they were condemned as HIV+ by the whole village when their mothers died of AIDS. To avoid rumors and harsh words, they were not allowed to stay out or chose not to communicate with others after being discriminated against.

When talking about his mother's death, Xiaozhi (male) answered:

She was infected by a blood transfusion and passed away when I was seven. I forgot how I felt because I knew nothing about what it meant to me... I did not

miss her that much after I went to the Green School at nine because I was loved by the teachers and peers there.

For Xiaohua, she once suffered a severe life-threatening paroxysm due to AIDS, constituting part of the unhappy memories of her childhood. She had enrolled in a local state primary school before she was diagnosed with HIV but was asked to leave after she came back from hospital treatment.

I was put in a corner in the classroom by my teacher at the state school. My classmates went around me or even spat at me. After I was kicked out, my dad (foster father) went to the school and argued with the headmaster. But the headmaster emphasized that he could not run the school just for me...I was not that eager to go to school. (Xiaohua, female)

Due to these stigmatized experiences, Xiaohua's self-protection mechanism was thus established to detect and respond to the environment.

In their early life, the vulnerability of the two participants is associated with orphanhood, individual stigmatization, and discrimination from the community. Although the informants mentioned many times that it was difficult to recall what had happened, and they have been able to relieve pain caused by agonizing memories, their experience of parental loss and the stigma attached to being HIV-infected has shaped part of their identity inevitably.

## **Phase 2: The positive development of youth identity with support at the special school**

Both participants noted that they have lived at the special school for over ten years and attained abundant support. The classmates with the same status and teachers who knew them well have become the primary sources with whom they share feelings and concerns, instead of their families in this stage.

The first two teachers at the Green School wore gloves and face masks when teaching us, but our principal found this and dismissed them. I no longer felt distraught since I came here. I think no stigma is the most important. I could see the care, warmth, and love there which I had not experienced before. Also, I consider my peers as the backbone of my life. (Xiaohua, female)

However, the exclusive environment also affected their lives in some negative ways. Xiaozhi thought that the school hampered their communications with the outside world, and Xiaohua affirmed this view by saying, "It seemed like you were trapped there." To solve this, the two interviewees indicated that the school has fully used the donations and was getting help from volunteers to enrich their campus and off-campus activities. For instance, the students could visit tourist attractions or participate in activities abroad

organized by the United Nations.

In addition, the Green School hires professional doctors and caregivers to support the student's medical needs, and this more systematic medical care plays a critical role in the children's growth. Xiaohua said, "All my friends were living well, which gave us confidence and hope."

In line with the results found by Petersen et al. (2010), adolescents who had strong social support appeared to be better at coping with HIV. The school thus played a notable role in the exploration of a sense of self for HIV+ adolescents.

### **Phase 3: An ongoing process of building a sense of social belonging at a mainstream university**

The two interviewees expressed that they experienced unprecedented pressure while making friends, especially related to disclosing to their friends at the university. While Xiaozhi insisted that he would never disclose his status because this brought a sense of security, Xiaohua struggled to tell her close friends the secrets, but ultimately gave up and was inclined to disguise the truth.

The avoidance of voluntary disclosure of both participants reveals that even though they were relatively well protected by the Green School, the nightmare of being stigmatized when they were young still badly affected their behaviors, although they refused to envisage or admit it.

Regarding their growth after enrolling in mainstream higher education, Xiaozhi responded that he has been drawing strength from the wider society. Xiaohua acknowledged that she is learning how to transform from relying on others to being independent. Both interviewees said they were excited about the future, a future with hopes and anticipation. It seems that Xiaozhi and Xiaohua open up themselves to society on the one hand and build up the "firewall" to resist the potential harm from the majority groups on the other hand.

The results of the interviews also show that the context shapes the social identity of the participants because of their low social status and negative distinctiveness of PLWHA. Nonetheless, the Green School provided a stable environment and instilled education on HIV knowledge, facilitating them to resist the threat to self.

### **Limitations**

This study has limitations as follows. First, the small sample size makes these findings less generalizable to other related research. Second, the issues of identity are individual and sensitive. Interviewing via Skype makes it less likely to observe non-verbal indicators

and thus may affect the data's validity.

### **Future research**

HIV+ young groups are at high risk of exposure to risk or even criminal behaviors. Scholars may need to increase the focus on this group by conducting longitudinal research and collecting data from multiple sources such as HIV-positive students, teachers, caregivers and people working in government and NGOs.



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