# **Indonesian Journal of Global Health Research**

Volume 6 Number S6, December 2024 e-ISSN 2715-1972; p-ISSN 2714-9749



http://jurnal.globalhealthsciencegroup.com/index.php/IJGHR

# STIGMATIZATION AND THE IMPACTS FOR INDIGENOUS PEOPLE WITH HIV/AIDS: A SCOPING REVIEW

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#### **ABSTRACT**

The global substantial evidence highlights that HIV/AIDS-related stigma is a barrier to HIV prevention programs, treatment, and support services. Overcoming stigma and discrimination is the main guiding principle in HIV prevention and control programs. Such overcoming is crucial, especially for indigenous people with HIV/AIDS because they are often marginalized. Based on this background, this scoping review aims to explore the HIV/AIDS stigma and its impact, especially experienced by indigenous people. : This scoping review was conducted from November 2022 to March 2023 by searching for manuscripts on PubMed, Science Direct, Cochrane Library, Wiley, Directory of Open Access Journals, ProQuest, GARUDA, and Gray Literature databases to identify HIV/AIDS stigma and its impact in indigenous people. Three reviewers independently screened the results. The extracted data were then mapped, categorized, and summarized. This study has identified that HIV/AIDS stigma in indigenous people includes curses, divine vengeance, and infectious diseases. Various impacts arising from stigmatization include concealment, discrimination, powerlessness, unequal life opportunities, and social rejection/isolation. Moreover, the stigma impacts the service system and health service providers. It is necessary to have a complex strategy supported by the involvement of health authorities, health workers, and indigenous communities to overcome the problems of HIV/AIDS stigma and to understand the culture of indigenous people to prevent and treat HIV/AIDS.

#### Keywords: HIV/AIDS; indigenous people; stigma

## How to cite (in APA style)

Suarnianti, S., BN, I. R., Suhartatik, S., & Kadrianti, E. (2024). Stigmatization and the Impacts for Indigenous People with HIV/AIDS: A Scoping Review. Indonesian Journal of Global Health Research, 6(S6), 627-634. <a href="https://doi.org/10.37287/ijghr.v6iS6.4933">https://doi.org/10.37287/ijghr.v6iS6.4933</a>.

### **INTRODUCTION**

Indigenous people living with HIV/AIDS are often marginalized and excluded from accessing health services (Arrey, 2018). Ethnic diversity with broad cultural customs is another factor that thwarts HIV/AIDS care in rural areas. In the early years of the HIV/AIDS epidemic, the social consequences of stigma and discrimination against people with HIV are identified as a part of the "third stage of the epidemic"; the effort to address these consequences is considered a "central to the global AIDS challenge and disease" (Mann, 1988). More than 50,000 rural residents who live with people with HIV/AIDS need consistent access to timely and high-quality health care to manage their symptoms and improve their quality of life (Tuttle & Rydberg, 2022). Indigenous people urgently need special attention from public health workers and individuals in health facilities, schools, and non-governmental organizations (Holst et al., 2022). One of the fundamental factors for this problem is that indigenous people who are diagnosed with HIV/AIDS often do not receive good and adequate health care due to the lack of equitable distribution of facilities, resources, and medical personnel in indigenous areas; therefore, equal access to healthcare is needed to maintain or reduce the spread of the pandemic in all indigenous areas (Owan et al., 2022). HIV/AIDS, its complexity, and health problems in indigenous areas have made the stigma of HIV/AIDS in this community unavoidable; in fact, such a condition is a determining factor in the treatment (Ullah & Huque, 2022).

The global substantial evidence highlights that HIV/AIDS-related stigma is a barrier to HIV prevention programs, treatment, support services, and efforts to deal with its impacts (Rayanakorn et al., 2022)(Ferguson et al., 2022). The World Health Organization (WHO) also recognizes AIDS stigma as a significant barrier to HIV prevention efforts. Therefore, addressing stigma and discrimination is a key guiding principle in HIV prevention and control programs, especially for indigenous people living with HIV/AIDS (Organization, 2021). To date, many reviews have examined stigma and HIV(Lo Hog Tian et al., 2021; Rich et al., 2022), but only a few have synthetically mapped the literature that explores HIV/AIDS stigma in ndigenous people. The synthesis of scoping reviews of HIV/AIDS stigma in indigenous people is pivotal considering that the scoping review method is not effectively applied to methodology and reports applied in other disciplines (Thomas et al., 2020). Therefore, this study aims to explore facts about stigma, especially stigma in indigenous people living with HIV/AIDS.

#### **METHOD**

This scoping review investigated the stigma HIV/AIDS indigenous people. The joanna Briggs Institute (Pourmarzi et al, 2017) and scoping review methodology (Hatala et al, 2018) were referred to this scoping reviewThis scoping review investigated the stigma HIV/AIDS indigenous people. The Joanna Briggs Institute (Pourmarzi et al, 2017) and scoping review methodology (Hatala et al, 2018) were referred to this scoping review. The protocol of this scoping review was registered on PRISMA for scoping reviews, http://prismastatement.org/Extensions/ScopingReviews. This study used several keywords for the literature search, such as HIV/AIDS, Stigma, and indigenous people. The extensive search was conducted on PubMed, Science Direct, Cochrane Library, Wiley, Directory of Open Access Journals, ProQuest, GARUDA, and Grey Literature. After stigma HIV/AIDS had been identified, more specific search terms were performed to find stigma HIV/AIDS dianatara orang pedalaman. This review limited studies published in peer-reviewed journals from 2013 to 2023 and written in English.

To reduce the risk of bias, this review had three reviewers. The manuscripts were selected to review in two stages. The authors began by reviewing the title and abstract. The full-text article was then reviewed. The selection process was carried out using progressive inclusion and exclusion criteria, as presented in Figure 1 using the PRISMA. 767 potential articles were identified. This review excluded manuscripts not written in English, not following the research questions, being duplicated, not provided in full text, not discussing Stigma HIV/AIDS, and not following the research results. Thus, this study only involved 19 articles that met the inclusion criteria. The inclusion criteria referred to the PCC: population (indigenous people), concept (HIV/AIDS), and context (Stigma). This review employed the data extraction form developed by the Joanna Briggs Institute (Joanna Briggs Institute, 2015). Data yang diekstraksi dari 15 artikel dikumpulkan berdasarkan, negara, target study, desain penelitian, teknik sampel dan instrument pengumpulan data, yang diilustrasikan oleh distribusi frekuensi (Gambar 2, Tabel 1). Analisis temuan studi mengidentifikasi empat faktor utama yang mempengaruhi stigma, delapan ungkapan langsung pasien HIV/AIDS terkait stigma dan empat tema menyeluruh. Untuk deskripsi singkat tentang tema, ungkapan stigma dan studi yang diperinci berdasarkan tema, lihat Tabel.3

#### **RESULT**

#### **Study Characteristics**

This current study examined 15 articles published from 2013 to 2022. These articles included data on the geographic locations of indigenous people from various countries (Figure 2). The distribution of indigenous people with HIV/AIDS is as follows: Canada (n = 6), India (n = 4), USA (n = 1), New Zealand (n = 1), Zimbabwe (n = 1), Colombia (n = 1), China (n = 1), and

Iran (n = 1) (Figure 2). These studies were conducted in America, Asia, Africa, and Australia. Of the 15 studies, six of them employed cross-sectional methods. Meanwhile, three studies employed qualitative methods, two studies employed mixed methods, and four employed unavailable information methods.

#### **HIV/AIDS Stigma**

This review has found various kinds of stigma experienced by indigenous people with HIV/AIDS, including "curse", "God's revenge", and "contagious disease". HIV/AIDS is considered a fatal "disease" (not a disease syndrome) sent by God as a curse; moreover, it is believed that people are most likely to be infected by AIDS because they violate religious values, not due to sex trafficking, homosexuality, prostitution, or sharing drug injections (Woodgate, 2017). In fact, these are the greatest factors that cause HIV disease and transmission (Richards, 2004). In addition, indigenous people who uphold traditional beliefs consider that HIV/AIDS is caused by a witch's curse and is related to witchcraft (Philip et al., 2021). Besides, indigenous people misunderstand how HIV/AIDS is transmitted. They think that HIV/AIDS is transmitted through needles in cinemas, razor blades, and social contact, such as touching or shaking hands (Tristanto et al., 2022). This stigma has triggered discrimination and worsened the health recovery of indigenous people with HIV/AIDS (Manangsang et al., 2022).

# The Impact of Stigmatization Concealment

Concealment refers to efforts to hide HIV/AIDS disease to avoid stigma. Six studies have reported that concealment is related to stigma and identified five types of stigma: social aspects (Pourmarzi et al., 2017), self aspects (Hatala et al., 2018), structural aspects (Chan et al., 2017), associative aspects (Charles et al., 2012), and healthcare professionals (Datta et al., 2016). These studies only focus on indigenous people and report similar findings on concealing HIV/AIDS disease. Three of the six studies have identified direct expressions of stigma perceived by people with HIV/AIDS (Chan et al., 2017) (Hatala et al., 2018) (Pourmarzi et al., 2017). This stigma expression conveys the meaning of how indigenous people with HIV sufferers struggle slowly to express their disease. Although people with HIV/AIDS dream to reveal their condition after concealing it for years, they would rather stick their heads in the sand. This finding is similar to that of (Santiago-Rodríguez et al., 2021) who have revealed that indigenous people living with HIV/AIDS feel embarrassed about disclosing their illness. However, (Buys, 2020) have found that although almost all people with HIV/AIDS feel difficult or ashamed to express their illness, they still have a way to deal with it, namely exploring the relationships between the feeling of shame, fear, guilt, and stigmatization of HIV/AIDS by employing special references for indigenous people.

#### Discrimination, Powerlessness, and Unequal Life Opportunities

In the study (Skinner & Mfecane, 2012) said Stigma and discrimination are cruel social processes that provide a sense of protection for those in power, while increasing the burden on individuals or groups who are victims in the process. Stigma can be seen as a tool used by more powerful groups to protect themselves as human beings. Stigma in turn is built only to affect the direct recipient who is considered guilty, so that he deserves this discrimination (Douglas, 1995). Meanwhile, five studies have revealed stigma about powerlessness, discrimination, and/or unequal life opportunities. Moreover, these studies have identified five types of stigma: social aspects (Woodgate et al., 2017), self aspects (Mccall, Jane; Pauly, 2012), associative aspects (Rich et al., 2022), structural aspects (Nyamathi et al., 2013), and healthcare professionals (Benoit et al., 2019). All studies that have revealed powerlessness, discrimination by health workers, families, and the community, and/or unequal life opportunities focus on investigating indigenous people. For example, (Chan et al, 2017) have

discovered that participants reluctantly access health services because they are afraid of receiving judgmental and discriminatory attitudes from health workers(Mccall, Jane; Pauly, 2012)(Mccall, Jane; Pauly, 2012) (Nyamathi et al., 2013). Studies have discovered that people with HIV/AIDS have been discriminated against by family members (Zhang et al., 2019) and prejudiced by societal beliefs for years (Rich et al., 2022).

HIV-related stigma has its own unique qualities, and is compounded by the layering of other stigmas related to race, gender, homosexuality, drug use, and promiscuity. Discrimination is directed at communities perceived to be more affected by HIV, whether these are physical criteria such as skin color, gender, sexual orientation, occupation, such as prostitution, or geography, or even entire continents, such as Africa. Thus, stigma not only affects individuals who carry the virus, but also increases the exclusion of groups already stigmatized by HIV, such as gay men and blacks (Aggleton, Hart & Davies, 1989; Sabatier, 1988). In the early days of the AIDS epidemic in the United States, the apparent association of the epidemic solely with the gay community led to concerns that the community would be further isolated and the fight against discrimination was reversed. Additionally, in the case of AIDS, the threat of double stigmatization exists. A person can fall into more than one stigma category and therefore feel a double burden. Examples include a black gay man who is HIV-positive, or an HIV-positive woman who is physically disabled. Each of them will experience stigma in all different areas of the norm, with each point of stigma isolating them from different sectors of their community. So, efforts to combat HIV-based stigmatization must interact with the other stigmas that people experience.

#### **Social Rejection and Isolation**

Eight studies report social rejection and isolation (either social or self-isolation) and are associated with stigma. Moreover, these studies have identified all types of stigma: social aspects (Cain et al., 2013), self aspects(Rich et al., 2022), structural aspects (Saewyc et al., 2014), associative aspects (Datta et al., 2016), and healthcare professionals (Benoit et al., 2019). All studies discovering social isolation and rejection only focus on investigating indigenous people. People with HIV begin to withdraw when they find out that they are infected with HIV (Rich et al., 2022). Another study focusing on other rural people reports that people with HIV are afraid of being considered "dirty", "disgusting", or "excommunicated", "labeled", or "expelled"; as a result, they withdraw themselves from society (Hatala et al., 2018).

#### The Impact of Healthcare Systems, Services, and Providers

Four studies report stigma about health care systems, services, and/or providers. Moreover, they have identified two sub-themes: availability and accessibility as well as competence and value of healthcare providers. The studies have also discovered five types of stigma: social aspects, self aspects, structural aspects, associative aspects, and health professionals. A study deploys that people with HIV who visit health facilities frequently receive discrimination because the doctors do not want to touch them and they are rejected from obtaining health services (Nyamathi et al., 2013). This result is supported by another study reporting that people with HIV are rejected from gaining health services and discriminated against by healthcare providers (Benoit et al., 2019).

#### Family Support to Reduce Psychological Pressure due to HIV/AIDS Stigma

Support refers to the involvement of the family who helps indigenous people with HIV/AIDS restore their mentality. Strong family support is associated with better quality of health recovery (Cluver et al., 2022). The absence of family support causes people with HIV/AIDS to experience depression more often because family support is the most important aspect for them to live their daily lives and deal with HIV/AIDS. This statement is also confirmed by

(Seffren et al., 2018) who deploy that a higher level of family support is associated with fewer symptoms of depression and anxiety. Most of the studies report that HIV/AIDS stigma experienced by indigenous people is influenced by family support. This current study has identified the types of four previous studies. Overall, insufficient family support for indigenous people living with HIV/AIDS is associated with increased stigma. Meanwhile, depression due to the absence of family support has triggered people with HIV/AIDS to commit suicide. These findings are supported by (Gizachew et al., 2021) who argue that the depression experienced by people with HIV/AIDS possibly removes their rational thinking; as a result, they very easily end their life. This finding is also supported by (Akatukwasa et al., 2021) who state that indigenous people with HIV/AIDS often attempt to commit suicide because they are excommunicated by their families (Akatukwasa et al., 2021).

Faktor psikis dan fisik memiliki hubungan yang sangat erat. Kehidupan fisik yang stabil sangat mempengaruhi kestabilan jiwa dan jika fisik dalam kondisi sakit maka akan mempengaruhi kejiwaan seseorang. Pardeck et.al. (1998: 29) menyatakan, "Health is a state of holistic well-being. It means being connected in a fulfilling way with the natural and human world." (Sehat adalah suatu keadaan sejahtera secara menyeluruh. Ini berarti terkait dengan cara pemenuhan kehidupan dengan dunia yang alami dan manusiawi) Dalam Jurnal Psikologi Kesehatan, Mustafid Amna (2003) mengatakan, kesehatan seseorang tak hanya diukur dari kebugaran fisik, tetapi juga dari kewarasan psikis, serta kelancaran interaksi sosial. Bukan hanya itu, WHO (1984) telah menyempurnakan batasan sehat dengan menambahkan elemen spiritual. Dengan demikian, sekarang ini yang dimaksud sehat bukanlah hanya sehat dalam arti fisik, psikologik, dan sosial, tetapi juga sehat dalam arti spiritual. Dengan kata lain, merujuk kepada WHO, terdapat empat dimensi sehat, yakni bio-psiko-sosialspiritual.

### **Indigenous Areas Versus Urban Areas**

An indigenous area is identified as a factor influencing stigma. Six studies have identified five types of stigma and report that indigenous people with HIV/AIDS receive various effects of stigma. Moreover, these studies have proven that urban people could access voluntary counseling testing (VCT) facilities more often than indigenous people do (Erena et al., 2019). Moreover, it is found that strategies to reduce the stigma against indigenous people with HIV/AIDS continue to fail due to discrimination, fear, and injustice. A study has explored different impacts of stigma experienced by indigenous and urban participants; the result shows that indigenous people experience racism when they are in urban areas (Benoit et al., 2019). In general, studies involving indigenous and rural communities with HIV/AIDS have reported that suicide due to HIV/AIDS is more highly found in indigenous communities than in urban communities (LeMasters et al., 2020; Sudjaritruk et al., 2021). The results of this scoping review show that studies on stigma are mostly carried out in America. This is because the HIV/AIDS emergency which disproportionately occurred in America in the past has affected this continent more severely than other racial or ethnic groups in other continents (Laurencin et al., 2008). Stigma arises due to various factors which then hamper people with HIV/AIDS to access help. In addition, stigma tends to appear among indigenous people; for example, people with a low level of education have a low level of knowledge about HIV/AIDS; in fact, increasing knowledge can function as an important intermediary process to change the stigma on indigenous people (Girma et al., 2014). From various factors described, the HIV/AIDS stigma on indigenous people has a considerable impact on service systems, health service providers, and the quality of life, such as concealment, discrimination, powerlessness, unequal life opportunities, and social rejection/isolation (Chan et al., 2015). Such conditions create a social construction that devalues, gives labels, and connects the label to related individuals or groups (Girma et al., 2014). The United Nations Program on HIV and AIDS (UNAIDS) had developed a strategy called getting zero (zero infections, deaths, and discrimination), unfortunately, this strategy ineffectively solved the impact of HIV/AIDS

stigma (Srithanaviboonchai et al., 2017). The impact of this stigma is interrelated so that, in the future, it is necessary to have a strategy that further collaborates with health authorities, health care professionals, and the closest family; consequently, people with HIV/AIDS, especially indigenous people, can be reachable (Chan et al., 2015). In addition, stigma should be overcome by considering aspects of belief, culture, and local wisdom upheld by indigenous people. Such a strategy should be implemented because most HIV/AIDS stigma due to belief and culture is experienced by indigenous people (Akatukwasa et al., 2021)

#### **CONCLUSION**

In the future, it is necessary to have a complex strategy that should be supported by the involvement of health authorities, health workers, and indigenous people. The involvement of indigenous people aims to understand their culture to prevent and treat HIV. Finally, the reviewed articles highlight the importance of health workers understanding the trauma and history of indigenous peoples to provide appropriate care. Protective factors against HIV infection include having positive relationships, openly communicating with families, integrating cultural values and beliefs into HIV prevention programs, conducting supportive HIV education, and implementing HIV tests. These factors can prevent the impact of HIV on indigenous people worldwide.

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