

## Review Article

### Experiences of Married Men with HIV during the Early Phase of Diagnosis within the Context of Mandatory Disclosure: A Literature Review

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#### Abstract

Individuals living with HIV often reveal their diagnosis to someone at some point in their life. This review examines factors that affect disclosure in different countries and the impact of disclosure on relationships and individual's well-being. In addition, some countries have required individuals to disclose their diagnosis to their spouse or sexual partners during the initial stages of diagnosis or prior to engaging in sexual behaviour. Research studies involving countries with mandatory disclosure laws are discussed to examine their influences on individuals with HIV and whether the laws are effective in promoting safe sex behaviours. Lastly, implications of using the specific model of disclosure theory to examine the role of the mandatory disclosure as a mediating process in affecting the disclosure outcomes and areas of future research are proposed.

**Keywords:** AIDS; Criminalization; Disclosure; Experiences; HIV; Interpretative phenomenological analysis; Males; Mandatory disclosure

#### Introduction

There are an estimated 33.4 million people currently living with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) and more than 25 million people have died from HIV/AIDS since its discovery in 1980s [1]. There are a total of 2.5 million new infections every year worldwide. Countries such as Canada,

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England, Wales, Sweden, some states of the United States and Australia require individuals with HIV to disclose their diagnosis to their spouses or sexual partners and take necessary precautions (e.g., wearing a condom) when engaging in sexual acts with others. This may become a complicated and difficult process for individuals who found themselves being recently diagnosed with HIV as they have to come to terms with their diagnosis while contemplating how to disclose their diagnosis to their spouses and sexual partners [2,3].

There were many studies that explored different variables influencing HIV disclosure patterns, possible outcomes or consequences of HIV disclosure, such as changes in relationships with their family members and factors that could facilitate or hinder the disclosure process (e.g., stigma) [4,5]. Despite the prevalence of HIV-related research studies focusing on the disclosure behavioural patterns, few research studies explored the impact of mandatory disclosure on individuals' level of adjustment towards their diagnosis and how they continue to move forward with their life after disclosing to their spouse. The review will cover the concept of disclosure in healthcare (e.g., terminal illness, HIV), theoretical perspectives of HIV disclosure, factors affecting disclosure and the impact of disclosure. In addition, this review will evaluate research findings related to HIV-specific disclosure laws in different countries and discuss the impact of these laws for individuals with HIV on the disclosure process.

#### Disclosure of Illness

Sometimes, it can be a difficult process for individuals to disclose to their loved ones and family members after being informed of their diagnosis of terminal illness (e.g., cancer). Individuals sometimes lacked appropriate communication skills to inform their family and loved ones or experienced feelings of uncertainty because they feared receiving negative perception and possible rejection from others after disclosing to them [6]. Most individuals disclosed their terminal illnesses as means of receiving support and help from others while at the same time tried to regain a sense of self-esteem and control over their unfavourable circumstances. Kurowecki and Fergus found that women with breast cancer disclosed their diagnosis to their partners when they were in a newly committed relationship or during the dating process [7]. In doing so, the women were slowly reclaiming their sense of self and bodily esteem as well as evaluating the reaction of their partners towards their diagnosis before deciding whether to proceed further with the relationship further.

Sometimes, individuals disclosed their illnesses unwillingly in unfavourable circumstances for example, disclosing to their potential employers when applying for a new job. In addition, some individuals avoided disclosing to their colleagues because they did not want over preferential treatment or experience stigma from others. This was supported by the findings of the study conducted by Brohan et al., in which participants believed that the employers' lack of knowledge and awareness of mental health illness often led to negative outcomes such as being rejected for the job which could impact on their level of confidence [8]. Similarly, participants described feeling undermined in their work and viewed their diagnosis as a negative label that

influenced their colleagues to have a negative perception towards them. Hence, employees often disclosed their mental health illnesses once they established level of trust with their employers and became competent in their work.

The similarities in the disclosure patterns between individuals with terminal physical and mental illnesses were that they mostly disclosed to their family members to receive family support and help from their family members in managing their condition. In addition, most individuals with terminal physical and mental illnesses might likely experience feelings of uncertainty and doubt about the reactions from others after disclosure. A main difference between the different groups of individuals was that individuals with mental health illnesses might likely view their illnesses as a societal stigma, hence perceived possible negative outcomes of disclosure, for example being rejected and ostracized by others. Individuals who chose not to disclose likely feared the societal stigma of their illnesses and perceived their disclosure experiences would bring about unfavourable outcomes. These reasons will be further explored in the subsequent sections with regards to the diagnosis of HIV, a terminal physical illness with societal stigma, having a possible impact on the disclosure process.

## Disclosure of HIV Diagnosis

The negative social stigma and perception of HIV increased an additional level of difficulty for individuals living with HIV because they feared that others would assume a negative perception and attitude towards them, leading them to become ostracized and stigmatized by the society. This fear was compounded for individuals infected with HIV as a result of engaging in unprotected sexual intercourse with multiple partners because they bring about serious repercussions on their relationships with their spouses and family members when they choose to disclose. Men, who account for the majority of the infected HIV cases (76%), do not always disclose their serostatus or modify their sexual behaviours which leaves their sexual partner being unaware and in turn, increased the risk of being infected [9]. Although there is much public education and awareness to encourage an individual to receive HIV screening so that they can receive early access to treatment with lowered chance of health complications after being diagnosed, little emphasis is focused on promoting disclosure behaviour for individuals with HIV. Therefore, this group of individuals may struggle and lack communication skills in disclosing their diagnosis to their sexual partners and instead continued to engage in unprotected sexual behaviour.

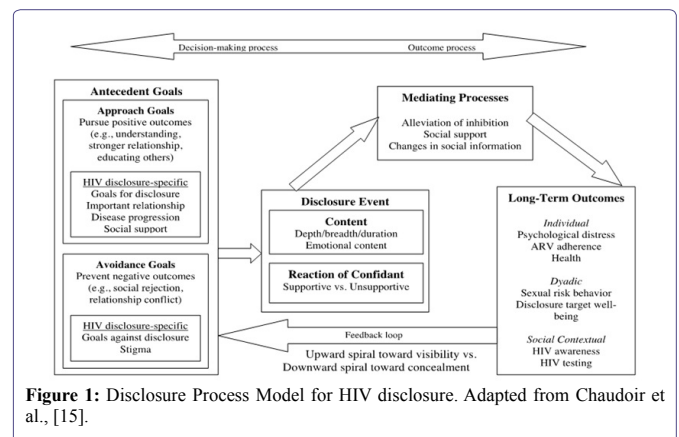
## Theoretical Perspective of HIV Disclosure

### Disclosure process model

Previous theories mostly focused on the disclosure behaviour such as understanding the factors that increase the likelihood of disclosure [10-14]. However, these theories fail to account for the differences in outcomes of disclosure which can be beneficial or detrimental to the individual with HIV. Individuals are sometimes forced to disclose despite knowing the costs of revealing their serostatus could affect their well-being and quality of life. Therefore, researchers were interested to explore the mediating processes that could affect the outcomes of disclosure and the impact on the individual's well-being and functioning.

Chadoir et al., developed the Disclosure Process Model (DPM) that incorporated the different elements of previous theoretical models

[15]. The model attempts to accurately capture the complexity of self-disclosure for individuals living with HIV/AIDS and how these individuals evaluate the outcomes of the disclosure process that may influence subsequent future disclosures to others. It comprises three main components namely, decision-making, the disclosure event and its mediating process and long-term outcomes. For the decision-making process, it is further broken down into two types of goals. Approach-focused goals promote the disclosure process (e.g., seeking support and understanding from family, improved relationship with family members and providing educational awareness about HIV/AIDS to others) while avoidance-focused goals promote concealment (e.g., perceived HIV stigma, fear of rejection and breakdown of relationship). These goals could be influenced by the societal norms and behaviour, culture and the severity of the illness. It is also noted that this theoretical model contends that there is a feedback loop that allows the individuals to evaluate their own experiences of the disclosure process and decide whether to repeat the process of disclosing to others or instead conceal their diagnosis from others (Figure 1).



Although this model provides the most detailed and comprehensive understanding of the disclosure process, few research studies have been done involving this model as compared to the consequences theory due to its recent development. A qualitative study consisted of 21 Haitian immigrants in New York were asked about their disclosure experiences in the United States and Haiti [16]. Results of the interview data found that participants had experienced both positive and negative outcomes such as social support, emotional relief, isolation and stigma. Results also indicated that the close relationship with someone whom they trusted is a mediating process to facilitate disclosure which was found to be consistent with the conceptual framework of DPM.

### Factors affecting HIV disclosure process

This section is a description of various factors affecting the HIV disclosure process and how the disclosure theories and models described in the previous section, can be used to explain the current research findings. A literature search of journal articles was conducted which examined the factors affecting disclosure across different groups of the population (e.g., men, women). A number of keywords were used during the literature search to identify relevant studies: HIV, men, women, HIV disclosure, disclosure outcomes, male/s, female/s and HIV Seropositivity. These search terms were used interchangeably and in various combinations. Three methods were used for this search which were (a) an electronic search on PsycINFO,

Science Direct, ProQuest, PubMed and Scopus and the academic search engine, Google Scholar; (b) a search of relevant journals for example: AIDS Care, Health Psychology, AIDS Behaviour, AIDS Patient Care & STDS, Journey of Family Psychology, Journal of Acquired Immune Deficiency Syndromes and etc., (c) a review of references in relevant articles to identify further potential studies.

Inclusion criteria for the identification of appropriate research articles were stated as (1) those that were published in English; (2) those that had a specific focus on disclosure experiences and outcomes across different populations and countries. Most of the research findings were summarized into these three main factors namely gender, culture and stigma. Gender and culture were further divided into sub-themes which would be discussed further in later sections.

## Gender

Current research methodologies use mixed-gender or single-gender samples to explore the differences in disclosure behavioural patterns and factors influencing disclosure in men and women which is discussed further in this sub-section.

**Gender differences in disclosure between men and women:** Much of the recent research on HIV disclosure, which focuses on the differences in disclosure patterns between men and women, has been done in the African continent where there is a high transmission rate. Deribe et al., conducted a mixed-method study in Ethiopia which indicated a high disclosure rate for both males and females [17]. Common reasons for disclosure between both genders were seeking social support from their spouse and common behavioural practice. Further quantitative results showed that reasons given by men to disclose were having a sense of duty to protect their spouse and avoided risk of transmission, while reasons given by women to disclose were their perceived stability in their relationship and their perception towards the severity of their symptoms. Quantitative results also indicated that women who were in the early stages of the disease, unmarried or less educated were less likely to disclose, while men who were concerned about their partner's negative reaction or did not report prior disclosure events with partner were less likely to disclose their serostatus. Additional qualitative interviews discovered that strong barriers against disclosure for women were fears of physical violence and raising their children on their own, while fear of exposure of their infidelity were strong barriers for men against disclosure.

These findings were consistent with another research study conducted in Uganda in which most respondents endorsed receiving social support from others and close relationships as the most important reasons for disclosure of HIV serostatus [18]. Most importantly, it was found that respondents indicated that having to explain obvious changes in physical appearances was also a reason for disclosure. Therefore, there are similar themes of fears of partner's reaction and negative consequences and the progression of the disease that have found to influence the disclosure process. These themes support the evidence of disease progression and consequences theoretical concepts in which both males and females have different factors that affect their decision-making process before they decide to disclose to their spouse. Moreover, it is a peer behavioural norm in African countries for both males and females to disclose their HIV serostatus to each other that might account for the high disclosure rate. Also, having some common reasons, such as seeking support and common behavioural practices, could influence both genders to disclose as explained by the social influence theory.

**Self-efficacy and disclosure between men and women:** Research studies also explored the influence of self-efficacy in the gender differences for disclosures. Self-efficacy is defined as the individual's level of belief or confidence to effectively carry out a specific behaviour under specified conditions [19,20]. In this case, research studies have explored the level of confidence in individuals with HIV to effectively engage in safe sex behaviours or making the decision to disclose their serostatus to others. Kalichman et al., conducted a questionnaire with 203 and 129 HIV positive men and women respectively and asked them to rate their emotional distress and self-efficacy in practicing safer sex and disclosure [21]. Results indicated that there were a sizeable number of participants (48%) who had not disclosed and were in exclusive partnered relationship for six months and longer. Although the results generally indicated that non-disclosure was associated with low self-efficacy and high emotional distress, men reported a higher self-efficacy in disclosing and refusing to engage in unsafe sex, while women reported a lower self-efficacy in disclosure that inhibited them in disclosing their serostatus. Likewise, participants who declined to disclose engaged in safe sex, as a strategy, to avoid disclosure. While the strength of this research was to explore the role of self-efficacy as a mediating process during disclosure, the researchers failed to explore the impact of relationships on disclosure and in-depth understanding in-depth of the disclosure event itself.

Other recent research in Hawaii showed consistent findings that perceived self-efficacy in decision-making was associated with disclosure in men and women [22]. However, there was a difference in the safe sex self-efficacy as men who disclosed were more likely to engage in safer sex practice than men who declined to disclose. Likewise et al., found similar results that participants who did not disclose had a strong likelihood of not using condoms to reduce HIV transmission [23]. Both self-efficacy for HIV disclosure and safe sex behaviours are related to non-disclosure as individuals with HIV might less likely willing to engage in safe sex practices with their spouses or partners because they feared of being found out and receiving negative reaction from them. Hence, the consequences theory likely provide the best explanation of individuals who perceived themselves having less confidence to disclose their diagnosis are more likely to selective attend to the negative outcomes of disclosure. This may have a societal implication because it can potentially highlight the worrying trend that disclosure is often avoided and not discussed between spouses and sexual partners, while people continue to engage in unsafe sex and increase the rate of transmission.

**Relationships and disclosure between men and women:** Other research studies explored the impact of relationships on the disclosure event between males and females and its outcomes. A quantitative research study conducted with 1092 participants in Uganda showed that participants who were married or co-habiting were more likely to disclose than those who were single, widowed or divorced [24]. Similarly, knowledge of a partner's serostatus, especially for individuals who knew their partner was infected with HIV, were significantly associated with disclosing their serostatus to their partner. Findings by Derlega et al., indicated that both men and women in their sample study endorsed the other's reaction as a reason for disclosure to intimate partner, while they endorsed privacy as a reason for not disclosing to their friends [25]. In addition, catharsis, duty to inform or educate and having a close supportive relationship were found to mediate the disclosure process for both men and women. These findings indicated disclosure to an intimate partner might bring positive



outcomes, such as sharing the 'burden' of diagnosis or encouragement from their partner to work towards accepting their diagnosis.

These findings were similar to research conducted in Kenya that showed married women or women in stable long-term relationship and had awareness of their partner's serostatus were more likely to disclose [26,27]. Besides understanding the relationship as a factor that affected the disclosure process, the researchers also conducted a qualitative study to explore the disclosure event. Participants reported disclosing their diagnosis as a result of declining health and men disclosed to their spouse directly when they were no longer able to conceal their symptoms. On the other hand, women mainly used indirect disclosure techniques, such as placing HIV-related pamphlets and medication around to serve as an entry point into discussing and disclosing their positive serostatus. Positive motivators, such as reducing risk of transmission and accessing early treatment, were found to facilitate positive behavioural outcomes, such as increased condom use or increased concern or kindness by partner. Barriers, such as fear of abandonment, being blamed for acquiring HIV and stigma, were likely to contribute towards negative outcomes, such as separation and conflicts with partners. The strength of both research studies was that different techniques of disclosure were explored and the reasons behind the preference of one disclosure technique over another were also explored between men and women. The limitation of these studies was that only one member of the couples was interviewed and thus the researchers were unable to validate the reported responses or actions of the partner.

Findings of research studies also indicated that some participants required healthcare professionals or friends to assist in the disclosure because they were afraid of the reactions from their partners or less confident about their communication skills. This technique was most useful in cases when the individuals predicted a high risk of negative outcomes or needed additional resources and support for them to work towards the acceptance of their diagnosis. Chen et al., interviewed 29 participants from China to explore the role and types of support that healthcare professionals provided and their impact on the individuals with HIV [28]. Qualitative findings showed that participants had highly favourable impressions of their healthcare professionals and trusted them in the management and disclosure of their condition. In addition, the researchers found that the relationship between the individuals with HIV and their healthcare professionals had a significant impact on their positive outcomes and promoted disclosure to their family members. Similarly, Rujumba et al., found that most HIV-positive women requested healthcare professionals' expertise and support in disclosure and felt that counseling should be provided to promote disclosure [29].

Although, the Disclosure Process Model was not used as the theoretical model to explain disclosure behavioural patterns for these research studies, findings of these studies indicated support and could be used to explain how the disclosure event could influence the positive and negative outcomes in this research. Meditating processes, such as the involvement of healthcare professionals and a supportive intimate partner, could have a role in facilitating positive long-term outcomes or reduce the barriers to disclosure.

**Experiences of disclosure in women:** Researchers explored the experiences of disclosure and its impact (e.g., coping and adjusting to their new identity) in women. Rouleau et al., conducted a phenomenological study with seven Canadian women and discovered several

themes [30]. Some examples of themes included having self-respect and autonomy in deciding when to disclose, fear of the unknown future and exposing themselves to social stigma and exclusion following disclosure. Most women admitted that disclosure was a painful process and suffered the burden of keeping the secret. Thus, they tried to establish control over the disclosure process, such as limiting the information shared between the people whom they chose to disclose. Another qualitative study conducted in China with 26 women also explored how Chinese women navigated the social stigma and the impact of disclosure in their relationships [31]. One woman reported wishing to be diagnosed with cancer instead due to perceived shame from being diagnosed with HIV. Other women withdrew from their social and work lives to avoid accidental disclosure. Lastly, findings also reported that outcomes of disclosure could have varying positive and negative consequences as some women experienced dissolution of their marriage, while others received more help for their care and deepening of relationship with their partner. These results indicated that although both participant samples came from different cultures, there were similar themes of HIV stigma, fear of unknown outcomes following disclosure and strategies to exert control over the disclosure process. Although these research studies did not have any theoretical framework to explain their findings, it might be a possibility that these findings showed supporting evidence for the different components of the Disclosure Process Model in women with HIV as they attempted to decide whether or not to disclose through weighing the different kinds of goals which could contribute towards possible positive and negative outcomes. Also, women who were found to explore varying strategies to facilitate disclosure to their spouses or partners were more likely to have positive outcomes.

**Sexual orientation and disclosure in men:** Most research studies explored both genders or solely women's experiences and factors affecting disclosure. Current research that consisted only male participants has primarily focused on gay men and their experiences of disclosure to their family members and friends. Like women, gay men also faced challenges in disclosure. Findings of the research study conducted by Wei et al., indicated that majority of gay men were found not to disclose their serostatus and that non-disclosure was highly associated with casual sexual partners and drug use [32]. Similarly, having a lack of knowledge about their partner's HIV serostatus was also associated with non-disclosure in gay men. Ethnic differences with disclosure in gay men were also explored. A qualitative research study explored the barriers of disclosure in HIV-positive Asian gay men and found three main barriers of disclosure, which were protecting family from shame, not wanting their family member to help them out of obligation as a result of their illness and avoid communicating highly personal information [33]. Moreover, there was a lack of translated HIV-related information which could facilitate the disclosure process.

Another study conducted by Bird et al., used measures of sexual behaviour to explore any significant association with disclosure rates in African-American and White males [34]. Results of this study indicated that African-American males were less likely to disclose than Whites, however those who disclosed were reported less likely to engage in unprotected sex. These results might likely indicate that African-American gay men were perhaps more likely to experience HIV-related stigma and chose not to disclose to their sexual partners. Findings of this study were also consistent with a qualitative study, using grounded theory approach, conducted in London with African participants, which showed themes indicating how this group

of participants juggled with the dilemmas of disclosure and its impact on their social and intimate relationship (e.g., fear of isolation from friends and family members) [35]. Hence, these research studies showed that although there were slight differences in factors that affected disclosure in gay men, disclosure remains a difficult and challenging process regardless of gender or sexual orientation.

**Experiences of disclosure in men:** Although the majority of the research studies focused on gay men, there were some research studies that explored the disclosure experiences of heterosexual men within the context of their marriage or partnerships. Dageid et al., interviewed 23 HIV-positive self-identified heterosexual South African men to explore the influence of masculinity on disclosure [36]. Results, using thematic analysis, indicated that they mostly delayed testing and seeking help until they were unable to hide their symptoms to avoid being perceived as being weak by the community. Moreover, these men declined to disclose because they did not want to take on the sick role that would threaten their sense of identity as a family provider following disclosure, thus viewing non-disclosure as a strategy to protect their family members from worry and stigma.

Similar research findings showed that men with a higher severity of HIV/AIDS symptoms were more likely to disclose to their mothers after they were unable to conceal the symptoms [37]. Also, highly educated men were found less likely to disclose, which indicated possible higher levels of coping skills and an unwillingness to worry their family members. Therefore, these research findings indicated that men were neither willing to undergo testing nor disclose to their family unless their disease progressed till it became difficult to conceal their symptom, hence supported the disease progression theory. Despite this, there was another probable explanation as findings of these two research studies also indicated that men weighed the perceived benefits (e.g., need for support) and costs (e.g., HIV-related stigma) before deciding to disclose, thus providing some evidence for the consequence theory as well. Although these research studies showed mostly negative outcomes, there was some evidence of positive outcomes (e.g., familial support and safe sex behaviours) following disclosure. While both research studies had only a small number of participants, these results were consistent with the current literature that disclosure might contribute towards negative outcomes, leading men to perceive disclosure as a threat towards their social and family role, hence deterring men from telling their family members as a way of protecting them.

## Culture

Many research studies explored the role of culture and ethnicity as factors that influence the disclosure process. This sub-section discusses how culture is a mediating process that influences the individuals in deciding the person to tell. Also, different cultures might have different beliefs towards the different modes of HIV transmission which could have an influential role in the disclosure process.

**Target of disclosure:** Individuals living in different countries show different preferences towards the choice of person they want to share the information with within their gay culture. An early research study conducted by Hays et al., indicated that gay men were more likely to disclose to their partners and close friends than to family members [38]. Similarly, other research showed similar findings that gay men, regardless of ethnic cultures or living in different countries, were less likely to disclose to their parents and other family members and

instead were more likely to disclose to friends [33,35,39-41]. This could possibly indicate that most gay men sought emotional and social support from their friends within their own gay culture because they were more likely to find acceptance of their sexual orientation and identity as compared with their families. Most of these studies were limited to gay men and the findings lacked generalizability to other groups of population, other research conducted in Quebec and South Africa with heterosexual men and women, showed that most individuals disclosed to their partners instead of their friends [30,36,42]. The similarities in these findings indicated that family members (e.g., parents and relatives) were often not the preferred choice as confidantes with whom to share the information.

However, research conducted in Asian countries with collectivistic cultures showed differing findings. In collectivistic cultures, individuals are more likely to emphasize interdependent relationships to their ingroups (e.g., their family members) and aligned their personal goals to meet the goals of the ingroup as compared to individuals in individualistic cultures [43]. Chandra et al., carried out a quantitative study with South Indian participants to explore factors affecting disclosure and found that majority of the participants chose to disclose to their family members (e.g., parents and siblings) and only a small minority (7.5%) disclosed to friends [44]. Another qualitative research conducted in China by Li et al., with interviews of 30 individuals with HIV found that the disclosure process was a family matter within individuals who either experienced involuntary disclosure in which their family members (e.g., parents and siblings) were informed of the diagnosis first before telling the individuals of their diagnosis or voluntary disclosure process in which the individuals typically chose to inform their siblings and parents instead of their spouse [45]. This was further corroborated with a follow-up research study in China using a sample of healthcare professionals who felt that family members, excluding their spouse, should be notified of the diagnosis first before informing the infected individual because it benefitted the individual to cope with themselves better after receiving his or her test result [46].

Researchers of these studies indicated that individuals in collectivist cultures with strong beliefs in family values were more likely accepting of their family being informed because they rarely made decisions without the involvement of their family and often shared their experiences with them [47]. This was further supported by Chen et al., in which they emphasized the differences between Western and Chinese values in which individualism and privacy were held with lower priority over family beliefs and values [28]. Although these research studies did not explore the use of disclosure theories, the use of the social influence theory offered the most likely plausible explanation or framework model that determined how different cultures and societal influences played an important role for individuals with HIV to decide whom they wished to disclose.

Likewise, the involvement of family in supporting individuals with HIV after disclosure was explored in a qualitative research conducted by Lim in which he explored the lived experiences of four HIV-infected men in Singapore [48]. He found that all of them had difficulties adjusting after acquiring a new social identity of a person with HIV and experienced intense feelings, uncertainty and dilemmas that impacted on their relationship with their family, friends and colleagues. Three of the men in the study received positive outcomes of strong family support after disclosure which helped them to face

the health challenges, while one man received negative outcomes of strained relationship with family following disclosure which contributed to his low confidence and little willingness to fight the disease. Although the research study had only a small number of participants, it offered a detailed insight into the lived experiences of individuals with HIV in Singapore and how the involvement of support from family could contribute towards the individuals to experience hope and determination in leading their life as a person with HIV.

**Modes of transmission:** Some research studies explored whether the modes of HIV transmission might have an influence on the disclosure rates in HIV in different countries. In Taiwan, Ko et al., interviewed 105 men with HIV to ask about their experiences of disclosing their serostatus to friends, family and other people and described the consequences and perceived responses after disclosure to each person [49]. Injection drug users were found to have the lowest disclosure response rate (21%). Gay men were found to disclose to their friends immediately after their diagnosis as compared to heterosexuals and injection drug users who majority took a week. Heterosexual HIV-infected individuals had the highest negative outcomes (56%) following disclosure. However, there were research limitations, which included a small sample and the use of convenience sampling with low response rate, both of which could introduce selection bias to influence the results.

Another quantitative research conducted in Russia with men and women showed that the majority of men who identified intravenous drug use as their mode of HIV transmission were more likely to avoid disclosure and less likely to receive medical treatment [50]. This result could also be attributed to selection biases in the recruitment of participants for the study because active drug users in Russia were excluded from receiving medical treatment for HIV and hence saw little benefits to disclose their diagnosis. Despite these selection biases in their results, both Ko et al., and Davidson et al., research findings highlighted that individuals who acquired HIV through drug use were most likely unwilling to disclose [49,50]. However, the possible reasons behind these findings were unknown and a possible explanation could be that HIV diagnosis was perceived as socially unacceptable and regarded as a punishment for promiscuous sexual behaviour and illegal drug use. However, more research in this area is needed to explore in detail the disclosure patterns among individuals with different modes of HIV transmission and comparison of countries with different drug laws.

## HIV Stigma

Research showed that HIV stigma was one of the most prevalent predictors that inhibited HIV disclosure and affected the quality of care and support that the individuals received. A research study conducted by Asiedu et al., to explore the impact of HIV-related stigma in Ghana found that women appeared to experience a greater negative impact of the stigma as compared to men [51]. In addition, they found that men reacted negatively towards their wife when they were diagnosed with HIV, as compared to women who were forgiving and compassionate towards their husband when they were diagnosed. Likewise, findings also indicated a societal acceptance for men to become diagnosed with HIV through sexual transmission but women were perceived as immoral and less tolerated when found to be diagnosed with HIV that left them feeling ostracised. Similarly, findings from qualitative research in Thailand showed that perceived stigmatization, shame and fear of rejection were barriers towards disclosure

and women in Vietnam were more likely than men to experience discrimination (e.g., denied health services) despite having laws that prohibited discrimination against individual with HIV/AIDS [52,53]. Skinta et al., conducted an interpretative phenomenological study and interviewed three HIV-positive gay men to explore their experiences of stigma and social support [54]. Findings indicated that they found difficulties initiating and establishing new relationships due to elevated levels of felt stigma and social marginalization which negatively impacted on their well-being. The strength of this study was that the researchers further explored how these individuals attempted to break away from the stigma and established a new identity through exploring their value-directed goals. Thus, participants reported using strategies to avoid becoming overly affected by the HIV stigma, such as being involved in spirituality and organized events to create HIV-related awareness. Another research study, which used thematic analysis, involved 23 heterosexual men in South Africa. Results found that stigma, fear of rejection and discrimination were some of the reasons that they declined to disclose to others while at the same time were struggling and renegotiating their own notions of masculinity within their culture [36]. Hence, individuals' experience of stigmatization and ostracism within their culture could have an influence in their willingness to discuss and disclose their diagnosis, as evidenced by social influence theory and positive outcomes following disclosure, for example increased social support, can facilitate the disclosure process.

Despite the high prevalence of stigma towards HIV in many countries, some individuals were still willing to disclose their diagnosis to others and experience some positive benefits as a result. Paxton conducted a qualitative study in Australia with 49 participants from diverse nationalities and cultures who felt shameful, loss and a sense of worthlessness after diagnosis and before disclosure [55]. As such, they became fearful and guarded in order to prevent the secret of their HIV serostatus from unintentionally disclosed and experience negative repercussions. However, participants found that with time passed by, they decided to disclose publicly to small groups of people and sometimes to the media, despite the presence of stigma and felt a sense of relief after revealing their burden of the secret. In addition, most of them developed new meaning of their lives (e.g., having a sense of purpose) and created a new identity of becoming a spokesperson to create awareness and understanding of HIV which gained greater acceptance from their community. Similarly, Mfecane found that married men with HIV in South African experienced positive reactions when they disclosed their serostatus despite their initial perceived negative fears of discrimination and stigmatization from their community [56].

Despite receiving negative outcomes after disclosure to others, such as experiencing rejection from others due to stigma, heterosexual women and gay men experienced few regrets after disclosure because it facilitated them coming to terms with their diagnosis and improved their level of coping and well-being [57,58]. In fact, Holt et al., found that most individuals used disclosure as way of coping and often repeated the process to disclose to other individuals to facilitate self-acceptance of their condition [59]. This research evidence provided support for the Disclosure Process Model because it highlighted the biofeedback loop whereby individuals evaluated the disclosure process and developed effective coping strategies to facilitate positive outcomes the next time they disclosed.



## Mandatory HIV Disclosure Laws

Due to increasing rates of HIV transmission, some countries have introduced laws requiring HIV-positive individuals to disclose their diagnosis to their spouse or sexual partners. For example, 24 US states enacted HIV-specific laws that made disclosure compulsory for an HIV-infected person to inform their diagnosis to their sexual partner before engaging in sexual activity [60]. Penalties for breaking these laws ranged from a \$2500 fine or less than 12 months to up to 30 years in jail depending on the severity and intent of the crime. Most research on HIV mandatory disclosure laws focused on three main areas: 1) whether individuals with HIV were aware or understand the law; 2) impact of criminalization on the lives of individuals with HIV; 3) effectiveness of the law (e.g., in reducing rate of sexual transmission) which will be discussed further in this section. In addition, this section will discuss the impact of the period between diagnosis and disclosure on individuals with HIV and lastly, explore implications of mandatory law on the theoretical processes of disclosure.

### Awareness of the Law

Galletly et al., asked 384 HIV-positive participants living in a specific US state with disclosure laws to complete an anonymous, self-report questionnaire that assessed their awareness and understanding of the law and the sources from which they received information about the law [60]. Results indicated that participants had a high understanding and awareness of the laws, as well as reported that their case manager discussed the law with them. However, the limitation of this study was that it was a self-reported questionnaire and the researchers did not explore the disclosure rates in this group of participants and the association between the awareness of the law with disclosure rates. Another research study conducted in Sweden explored the perceptions towards the mandatory need to disclose to sexual partners in young adults with HIV between 17 to 24 years of age and found that most of them were worried about the consequences of the law and found mandatory disclosure to be a burden [61]. Although young adults with HIV tried to lower their risk of transmission to others, they struggled with disclosing their partners of their HIV serostatus and had difficulties communicating the need to engage safer sex behaviours. Though they acknowledged the necessity of the mandatory disclosure law, they perceived that the impact of this law had placed an additional social responsibility and burden of having to enforce safe sex practices with their partner. Also, they would be criminalized even if they engaged in safe sex behaviour and chose not to disclose their serostatus. Hence, they often repressed or denied their sexual needs through refusing to engage in any sexual behaviour so as to avoid disclosing their serostatus to others. In some cases, the young adults used their fear of being criminalized for non-disclosure as a strong deterrent to avoid engaging in sex or seek anonymous sexual contacts through the Internet to reduce their chances of being caught for non-disclosure. Therefore, the strong awareness of these HIV laws in young adults with HIV might bring them feelings of fear that they would become criminalized for non-disclosure and refusal to engage in safe sex practices because of their lack of confidence in negotiating using a condom or disclosing their serostatus to partners.

On the other hand in England and Wales, research findings found that gay men were sometimes confused and misunderstood the disclosure laws [62]. In addition, almost half of them reported that the possibility of being prosecuted for non-disclosure was not likely to change their sexual behaviours and became less willing to disclose

their HIV serostatus. Therefore, most individuals with HIV often avoid disclosing their serostatus despite having awareness of the mandatory disclosure law and use strategies (e.g., avoiding sexual intimacy) to ensure that their positive serostatus remain a secret.

### Impact of Criminalization

There has been much debate in the research literature that criticizes criminalizing HIV transmission as a result of the disclosure law. Some authors argued that criminalizing HIV disclosure had an adverse impact on individuals with HIV. Qualitative research conducted by Adam et al., with 122 individuals with HIV in Canada indicated having a heightened sense of vulnerability and fear, which negatively affected their social relationships such as initiating an intimate relationship [63]. Other authors argued against the necessity of the HIV-specific laws since existing laws were found to be adequate to prosecute those with the intent to harm others through sexual transmission, therefore concluded that the existence of these laws were promoting an increased HIV stigmatization and fear towards this group of vulnerable population [64,65]. Moreover, these studies indicated that some individual's might not be aware of their diagnosis and unwittingly prosecuted due to their non-disclosure, which enforced the perception of punishing the behaviour despite having insufficient evidence to prove intent. Likewise, it is difficult to comprehend that only sexual HIV transmission is criminalized but other forms of transmission, for example intravenous drug use, remain unaffected. Therefore, mandatory HIV disclosure remains a controversial issue as researchers are not convinced that criminalizing HIV sexual transmission can adequately address the societal implications and reduce negative impact in individuals with HIV.

### Effectiveness of the Law

It is widely believed that the reasons for having HIV mandatory disclosure laws are to reduce HIV sexual transmission and encourage safer sex practice since sexual transmission accounts for the highest percentage as the common mode of HIV infections. Therefore, there has been much research that explores the effectiveness of the disclosure law in reducing sexual risk-taking behaviour and promoting awareness of engaging in safe sex practices with a partner. Bird et al., found that men who disclosed to their partners had a significant reduction in sexual transmission risk because they were less likely to engage in unprotected sex [34]. However, Simoni et al., found that 15 out of 23 studies met the satisfactory rigour of data to examine the relationships between disclosure and safer sex practices [66]. They found that most studies had several methodological limitations such as not taking into account the type of partnership (i.e., married/cohabited/casual) which might confound the results. Also, some studies had inconsistent operational definition of unprotected sexual behaviour as participants were unclear the definition of sexual contact (i.e., oral/anal/vaginal intercourse). One of the main findings that the researchers found is that studies did not often take into account the social desirability of the participants' responses which they might response favourably, such as acknowledging that they had disclosed to their partner when they did not and agreeing that the law is effective to reduce HIV transmission. The implication of this meta-analysis was that most studies had poor methodological design study which the researchers indicated that the association between disclosure and safer sex practices remained not empirically supported. Instead, they asserted that good communication skills remained the necessary tool

for individuals with HIV to facilitate the negotiation of safer sex and reduce the HIV transmission.

Meanwhile, O'Byrne also conducted modeling analysis with the current research studies and arrived at similar findings that although the mandatory disclosure laws might prevent the risk of HIV transmission in small isolated cases, there was little overall impact that the laws could significantly reduce the HIV transmission on a population level [67]. Instead, there was some evidence that the use of mandatory disclosure laws could likely exacerbated the spread of HIV transmission because people were less likely to receive HIV testing and remained unaware of their suspected HIV diagnosis. Therefore, the implication of this study showed that HIV mandatory disclosure law might not promote the societal context of encouraging safer sex and regular HIV testing and instead reinforced the societal stigma and rejection of the individuals with HIV. This was further explained by Galletly et al., who argued that there was no significant evidence that disclosure was effective as a preventive strategy to reduce HIV transmission through condom use [68]. Instead, the disclosure law undermined efforts to reinforce the use of condom as a societal and behavioural norm and instead promoted HIV stigma and fear. Hence, there is insufficient evidence to conclude that the use of mandatory HIV disclosure law is an effective strategy to reduce sexual transmission and infection rates.

## Length of Time Between Diagnosis and Disclosure

Research studies found variation in the average length of time between diagnosis and disclosure which is an important factor that affects the disclosure process. Tom found that the majority of participants in Namibia (60%) disclosed within one week and only a small percentage disclosed after more than 12 months (3%) [69]. However, the participants were recruited from a specific sample of population receiving free medical treatment at the clinics and were asked to recall the first time that they disclosed to their sexual partners, which might lead to possible recall bias and social desirability, for example providing positive responses to ensure continuing free medical treatment that could affect the results. Other research studies with pregnant women showed that the majority of them disclosed within 14 to 30 after knowing that they were infected and men disclosed their serostatus in an average of seven days [13,27,49,70].

Other research studies showed that gay men, who knew their diagnosis for at least one year, had a higher likelihood of disclosing as compared to those who had a short time period between diagnosis and disclosure diagnosis [71]. Paxton found that heterosexual individuals rarely informed others immediately after diagnosis and often needed time to come to terms through sharing their fears with a counsellor [55]. Findings in her study, which explored the experiences of individuals disclosing their diagnosis to the public, indicated that the average time between diagnosis and public disclosure to other people besides their family members and friends was 2.6 years with females having a shorter time frame (2.0 years) than men (3.4 years). Thus, there are different periods in which individuals with HIV are prepared to inform others of their diagnosis and with individuals being affected by the introduction of HIV-specific disclosure laws, there could likely be a decreased autonomy and sense of control for them in deciding when they are willing and comfortable to inform others. Therefore, it remains unclear whether these laws will facilitate or hinder the psychological processes and creation of a new self-identity after diagnosis in individuals with HIV.

There were mixed nature of findings on the length of time between diagnosis of HIV and HIV disclosure. Most research findings found that an average of seven to a month is a typical time period for the person to disclose their diagnosis to other while a small number of studies found that individuals took about one to two years before they were ready to disclose. It was noted that individuals with HIV diagnosis made the choice on their own in deciding when they were ready to disclose. Often, individuals who had close relationship with the targeted person that they wished to disclose often disclose within a shorter timeframe as compared to others who had a more distance relationship with the targeted person (i.e., a stranger).

## Implications of mandatory disclosure

The Disclosure Process Model provides the most suitable model to understand the implications of mandatory disclosure because it provides the explanation of how individuals weigh the pros and cons before deciding to disclose and at the same time, evaluate the outcomes of disclosure to decide whether they wish to repeat the disclosure process again to other people. The mixed nature of research findings in the time period between the diagnosis and disclosure suggest that other mediating processes or variables that could affect the outcomes of disclosure. Mandatory disclosure law is one of the possible mediating variable that could affect the outcomes following disclosure and influence the individuals in deciding whether they wish to disclose again. Most of the research findings on the average length of time in disclosure assumed that individuals made the choice to disclose willingly without coercion. However with the mandatory disclosure law, the decision to disclose is taken away from the individuals and it may be possible that some individuals struggle and are not prepared to disclose, yet are required to comply with the law to inform their spouse or partners. There is little current empirical evidence to know whether the mandatory disclosure law affects the sense of adjustment and coping in individuals with HIV as they are forced to disclosure and may be unprepared to accept the possible reactions and consequences of disclosure which likely inhibit them to repeat the same process of disclosing to others.

## Living with HIV Following Diagnosis and Disclosure

Research had also studied individuals' sense of adjustment and coping with their diagnosis following disclosure. Remien et al., summarized the challenges that individuals with HIV faced, such as struggling to make the appropriate treatment choices and adhere to their antiretroviral medication [72]. They also found that individuals with HIV struggled with maintaining a healthy lifestyle and may likely to have mood problems at some point in their lives. Gay men found that the diagnosis of HIV made them less desirable to initiate sexual encounters or establish intimate relationships with others, hence becoming less open and having to conceal certain aspects of the identity [35]. Frain et al., found that cognitive appraisal and family resilience were strongly associated in the quality of life with individuals living with HIV [73]. Individuals who had higher optimism and lower feelings of uncertainty contributed to a higher quality of life. Family resilience, such as acceptance of the diagnosis by the family members and family members providing social, emotional and financial support, were found to associate higher levels of optimism in individuals with HIV and mitigated lower quality of life. Therefore, individuals with HIV face lifelong struggles to cope with their illnesses, likely to experience mental issues and poorer health outcomes when their



experiences feelings of uncertainty and a lack of family support to manage their condition.

## Future Research

Although there has been much research that explores the variables and factors affecting disclosure between different countries, there is still limited research in Asian countries to explore the lived experiences of individuals with HIV during the disclosure process, especially in men. As most Asian countries are patriarchal societies in which men often take on the familial head of the household and are often the breadwinner for the family, it would be interesting to explore the possible shift in spousal and family dynamics following diagnosis and how the family adjusts to the changes following disclosure. Hence, a larger scale longitudinal study is recommended to explore the family dynamic changes during differing stages of the men's life as they learn to accept their new social identity of being a person diagnosed with HIV and disclose to their family and friends slowly over time.

Other kinds of research can also explore whether different modes of transmission has had any affect on the disclosure patterns and support that the individuals receive in helping them to fight their disease. Likewise, there are limited research studies that explore the impact of disclosure on individuals receiving the news of diagnosis from their infected sexual partner and the level of support that they provide for their infected spouse or sexual partner which could be explored through semi-structured interviews. A wider scale study, that involves a few countries with varying culture and societal norms across different population, is also recommended to explore in-depth individuals' preferences for the target disclosure and their reasons behind their choice. Likewise, future studies can also explore the experiences of youths being diagnosed with HIV and how they navigate the disclosure processes with their family members and friends. Other studies can also focus on countries with mandatory disclosure and explore its impact on populations with different sexual orientations and gender so as to understand the possible impact of mandatory disclosure on individuals' relationships with their family members, spouses or sexual partners. Lastly, a questionnaire or qualitative study can be done to explore the public or society's perceptions towards mandatory disclosure and their reactions when their friends or family members revealed their diagnosis to them.

## Conclusion

There has been much advancement in HIV research since the discovery of HIV in the 1980s. Although there are highly active antiretroviral medications to combat the spread of HIV to AIDS and maintain function of the immune system in individuals with HIV, there continues to remain no cure for HIV and HIV transmission continues to increase. Therefore, HIV has become an increasing societal issue as more individuals are living longer and relationships will become impacted when a new individual becomes diagnosed with HIV. Similarly, disclosure of a person's serostatus will increasingly become more common especially as more countries are deciding to implement mandatory disclosure laws as a strategy to prevent the risk of HIV transmission. Hence, individuals with HIV are finding it harder to conceal their diagnosis and might struggle with psychological issues of coping and being forced to disclose to their loved ones when they are not ready to do so. Thus, possible programmes or interventions may be developed in the future to reduce the level of HIV stigma and fear to facilitate individuals to feel comfortable and ready to disclose

within their own society while accepting their new self-identity following diagnosis.

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