Meta-Analysis of Disclosure Rates of Mothers Infected with HIV to Their Children: A Global Perspective

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Table of Contents

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Abstract

Background: With the advancement in HIV treatment, the quality of life of HIV-infected women has significantly improved, and HIV-infected women have been able to participate in childcare and assume social responsibilities. Research suggests that there are varying degrees of maternal HIV disclosure among HIV-infected mothers, and that these differences may be related to a variety of psycho-social factors. However, there is a lack of data on the overall disclosure rate.

Objective: The objective of this study was to conduct a comprehensive review and meta-analysis of the global prevalence of disclosure of HIV status to children among HIV-infected mothers, with the aim of establishing a foundation for preventing mother-to-child transmission (PMTCT), enhancing ART adherence among HIV-infected mothers, and improving overall survival quality.

Methods: We searched Pub Med, EMBASE, and Cochrane Library in English, and we also specifically searched CNKI, Wanfang Data, and VIP databases in Chinese for the studies of HIV women disclosure in China. Studies that published from January 1, 2003 to 2024 were located. Language restriction is English and Chinese. Key words include "HIV-infected", "maternal" or "mother" or "women" or "parent", "children" or "youth" or "adolescents", and "disclosure" or "inform" .

Results: Ultimately, 14 studies were included for review. Heterogeneity among the chosen studies was evaluated through chi-square tests and I2 statistics; and sensitivity analyses were conducted to assess the comparability of study results. The global HIV disclosure rate was 41% with a 95%confidence interval (CI) ranging from 30% to 52%. Subgroup analyses based on region and parental infection status showed that the HIV disclosure rate was 36% [95%CI:25%-49%] in 3 Chinese based study; 60% [95%CI:49%-70%] in 6 U.S. based studies; and 25% [95%CI:11%-43%] in 4 African based study. Furthermore, the HIV disclosure rate was 42%[95%CI:28%-57%] among families with only mother being infected with HIV across 9 studies; and 39%[95%CI:22%-59%] among families with both parents being infected across 5 studies.

Conclusions: Findings indicate that the disclosure rate of HIV-infected mothers to their children is higher in developed regions, and within families with only mother being infected with HIV. Further research efforts and policy development are imperative to support decision-making processes for HIV-infected mothers when considering disclosure of HIV infection status to their children. Clinical Trial: CRD42024531337

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Conflict of interest

All authors declare to have no conflict of interest.

Abstract

Background:With the advancement in HIV treatment, the quality of life of HIV-infected women has significantly improved, and HIV-infected women have been able to participate in childcare and assume social responsibilities.Research suggests that there are varying degrees of maternal HIV disclosure among HIV-infected mothers, and that these differences may be related to a variety of psycho-social factors. However, there is a lack of data on the overall disclosure rate.

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Results: Ultimately, 14 studies were included for review. Heterogeneity among the chosen studies was evaluated through chi-square tests and I2 statistics; and sensitivity analyses were conducted to assess the comparability of study results. The global HIV disclosure rate was 41% with a

95%confidence interval (CI) ranging from 30% to 52%. Subgroup analyses based on region and parental infection status showed that the HIV disclosure rate was 36% [95%CI:25%-49%] in 3 Chinese based study; 60% [95%CI:49%-70%] in 6 U.S. based studies; and 25% [95%CI:11%-43%] in 4 African based study. Furthermore, the HIV disclosure rate was 42%[95%CI:28%-57%] among families with only mother being infected with HIV across 9 studies; and 39%[95%CI:22%-59%] among families with both parents being infected across 5 studies.

Conclusions: Findings indicate that the disclosure rate of HIV-infected mothers to their children is higher in developed regions, and within families with only mother being infected with HIV. Further research efforts and policy development are imperative to support decision-making processes for HIV-infected mothers when considering disclosure of HIV infection status to their children.

Key words

HIV-infected mother, Disclosure rate, Global, Meta-analysis

Introduction

The objective of this study was to conduct a comprehensive review and meta-analysis of the global prevalence of disclosure of HIV status to children among HIV-infected mothers, with the aim of establishing a foundation for preventing mother-to-child transmission (PMTCT), enhancing ART adherence among HIV-infected mothers, and improving overall survival quality. A total of 1,072 studies published between January 1, 2003 and January 1, 2024 were initially searched from databases such as Web of Science, Pub Med, Embase and Cochrane Library. Ultimately, 14 studies were included for review. Heterogeneity among the chosen studies was evaluated through chi-square tests and I^2 statistics; and sensitivity analyses were conducted to assess the comparability of study results. The global HIV disclosure rate was 41% with a 95%confidence interval (CI) ranging from 30% to 52%. Subgroup analyses based on region and parental infection status showed that the HIV disclosure rate was 36% [95%CI:25%-49%] in 3 Chinese based study; 60% [95%CI:49%-70%] in 6 U.S. based studies; and 25% [95%CI:11%-43%] in 4 African based study. Furthermore, the HIV disclosure rate was 42%[95%CI:28%-57%] among families with only mother being infected with HIV across 9 studies; and 39%[95%CI:22%-59%] among families with both parents being infected across 5 studies. Findings indicate that the disclosure rate of HIV-infected mothers to their children is higher in developed regions, and within families with only mother being infected with HIV. Further research efforts and policy development are imperative to support decision-making processes for HIV-infected mothers when considering disclosure of HIV infection status to their children.

With the advancement in HIV treatment, the quality of life of HIV-infected women has significantly improved, and HIV-infected women have been able to participate in childcare and assume social responsibilities(1). The Joint United Nations Programme on HIV/AIDS (UNAIDS) shows that by the end of 2022, 39 million people were living with HIV worldwide, with 46% of new HIV infections occurring among women of reproductive age(2). According to the infectious disease surveillance data from the China Information System for Disease Control and Prevention (CISDPC), by the end of 2022, there will be about 23.2 thousand newly reported HIV/AIDS (Acquired Immunodeficiency Syndrome) cases among women in China in 2022(3).With the expansion of HIV testing and treatment, the quality of life of HIV-infected women has changed, and at the same time, infected women have been able to participate normally in life and assume social responsibilities(4). In 2019, The Lancet AIDS published a series of articles advocating that global health systems are struggling to cope with the increasingly complex healthcare needs of people living with HIV, and that the psycho-behavioral and social health aspects of informing their children about their infectious status is a challenge that deserves to be researched and addressed(4). Across multiple studies, HIV non-disclosure has been identified as a key barrier to HIV care engagement(5,6). Parental HIV disclosure, the act of parents living with HIV (PLH) telling their children about their HIV diagnosis, is a critical aspect of parent–child communication and is important for facilitating HIV treatment adherence(7). Informing children of their infection status is an important decision that involves family dynamics, societal attitudes and individual mental health(8). Research suggests that there are varying degrees of maternal HIV disclosure among HIV-infected mothers, and that these differences may be related to a variety of psycho-social factors(9-12). However, there is a lack of data on the overall disclosure rate. The objective of this meta-analysis is to offer a comprehensive overview of the prevalence of HIV-infected mothers disclosing their status to their children through a systematic review and meta-analysis. Findings can deepen our understanding on the crucial role of HIV-infected mothers in disclosing their status to their children and provide support to increase both the level and quality of disclosure.

Methods

Literature Search

We followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRIMSA) 2009 statement and the updated PRISMA 2020 guidelines to conduct this meta-analysis. The protocol was registered in the prospective register of systematic reviews (registration number: CRD42024531337).

We searched Pub Med, EMBASE, and Cochrane Library in English, and we also specifically searched

CNKI, Wanfang Data, and VIP databases in Chinese for the studies of HIV women disclosure in China. Studies that published from January 1, 2003 to 2024 were located. Language restriction is English and Chinese.Key words include “HIV-infected”, “maternal” or “mother” or “women” or “parent”, “children” or “youth” or “adolescents”, and “disclosure” or “inform” .

Eligibility Criteria

We included studies published between 1 January 2003 and 1 January 2024 that explored HIV-infected mothers informing their children of their infection status. We considered primary observational studies that used cross-sectional studies. Inclusion criteria were as follows: 1) outcomes included the number of HIV-infected women who have disclosed their HIV status to their children; 2) cross-sectional design; and 3) published in Chinese or English. We excluded narrative reviews, case reports, editorials and letters to the editor, reviews, and systematic reviews.

Data Extraction and Synthesis

Two independent reviewers conducted a thorough literature screening, strictly adhering to predefined inclusion and exclusion criteria. They then created a standardized data extraction form to collect relevant information. Inconsistencies were dealt with and consensus were reached by discussion among the expert committee. Data extraction for the selected studies included 1) bibliographic information such as title and authors; 2) study characteristic such as the study design and sample population; and 3) rate of disclosure of HIV status to children.

Risk of Bias Assessment

We assessed the methodological quality and risk of bias of included studies using the Agency for Healthcare Research and Quality (AHRQ)(13). We used the AHRQ to assess the methodological quality of cross-sectional studies. We scored the quality of the included articles according to the scale scoring guidelines and presented them in tabular form.

Statistical Analysis

We extracted study data relevant to the meta-analyses using a standard data extraction sheet. This information included study characteristics (e.g., study year, study duration, location, sample size, publication date,age of mother, number of children, age of children and family infection status), study results, and AHRQ quality scores.Data were analyzed using disclosure of HIV status to children as the primary outcome indicator, and analyzed in subgroups according to different regions and infection status of the parents' families. Heterogeneity was tested and fixed-effects model was used if $P<0.05$, based on I2 measurements, indicating no heterogeneity. Otherwise, a random effects model was used. Publication bias was assessed by generating funnel plots and Eggers' test. Data was analyzed using R Studio 2023.12.1.402 software.

Results

Selection Criteria

All records retrieved from the database were exported to Note Express V4. Duplicate records were removed, and titles and abstracts were used to screen relevant studies. We scrutinized the full text of the studies included from the initial screening to assess their eligibility. Finally, we assessed the methodological quality of studies that met the inclusion criteria and included them in the meta-analysis. The detailed flow is shown in Figure 1.

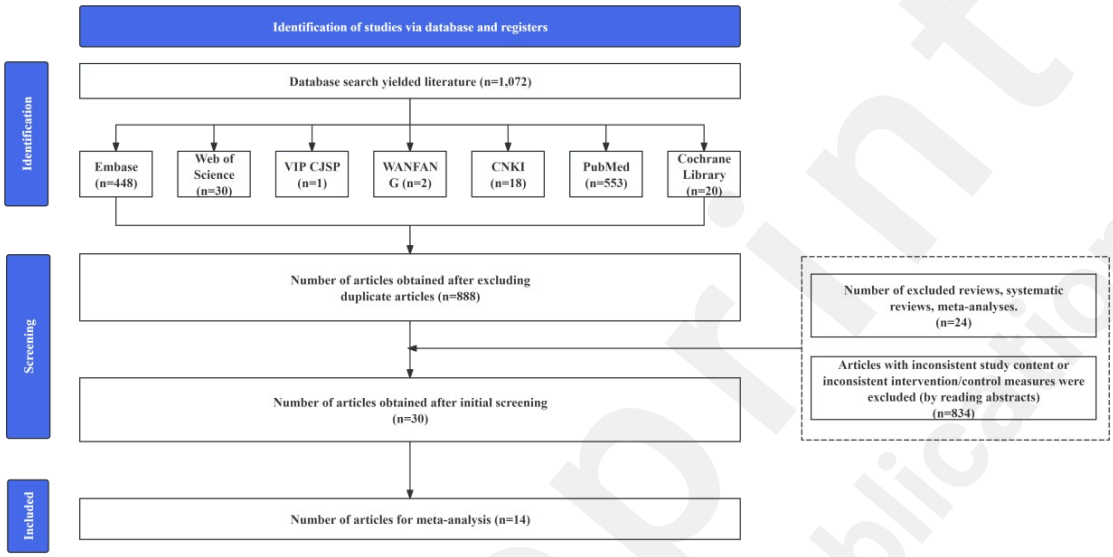

Figure 1 PRISMA flow diagram for the systematic review

Abbreviation:PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-analyses.

Characteristics of Included Studies

From an initial selection of 1072 published studies, 184 duplicates were removed; 858 were removed by reading the titles and abstracts; 14 met the inclusion criteria and were included for analysis, involving a total of 3,890 HIV-infected women(14-27). Detailed information of the included studies is presented in Table 1.

Table 1 Basic information of the included studies

Ref No.	Author[1]	Country/Region	Study size	Outcome (Disclosure)
1	Corona, R.2006	USA	453	200
2	Delaney, R. O.2008	USA	66	32
3	Delaney, R. O.2009	USA	90	63
4	Letteney, S.2004	USA	88	59
5	Letteney, S.2012	USA	101	75
6	Mugo, C.2023	Nairobi, Kenya	205	26
7	Nöstlinger, C.2006	European	1094	226
8	Osingada, C. P.2016	Kampala,Uganda	344	127
9	Ostrom, R. A.2006	USA	45	24
10	Palin, F. L.2009	South Africa	103	46
11	Wang, Q.2019	Guangxi,China	292	132
12	Zhao, J.2015	Henan,China	511	198
13	Zhou,Y.J.2015	Guangxi,China	93	22
14	Visser, M.2020	South Africa	405	50

Overview

The results of the Heterogeneity test showed that there was heterogeneity in the included studies, I^2=97%, P<0.01. The overall disclosure rate was 41 %, with a 95% confidence interval of (30%~52%) (Figure 2).

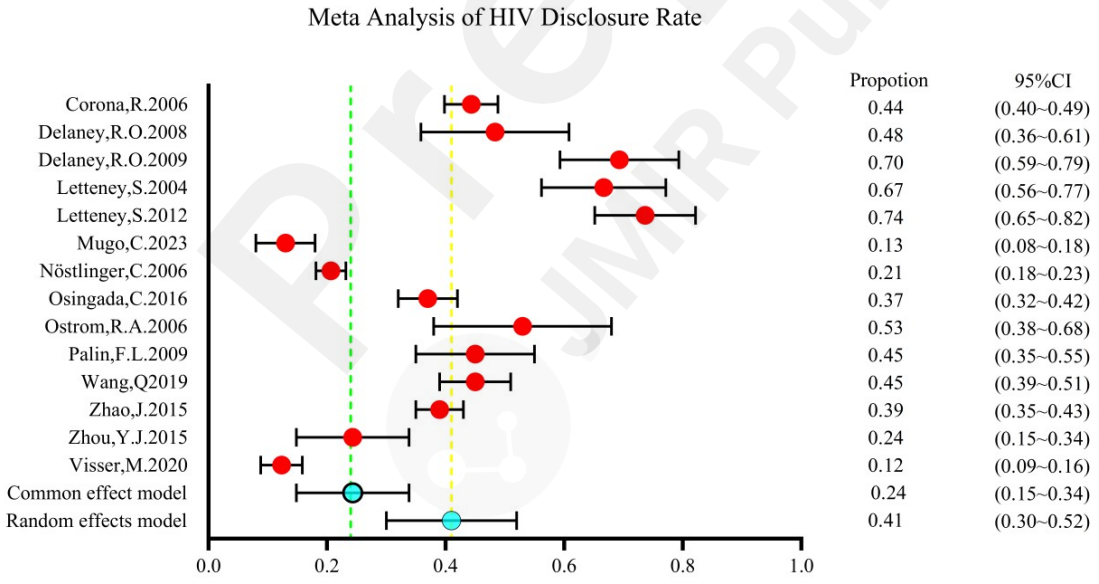

Figure 2

Sensitivity Analysis

Subgroup analysis was conducted based on regional and parental infection status. The overall disclosure rates for the 3 studies conducted in China were 36% (95% CI: 25%, 49%), exhibiting a

heterogeneity of 86%. In the United States, the overall disclosure rate for the 6 studies was 60% (95% CI: 49%, 70%), with a heterogeneity of 90%. For Africa, the overall disclosure rate for the 4 studies stood at 25% (95% CI:11%,43%), demonstrating a heterogeneity of 97%. Amongst studies where only the mother was infected with HIV, an overall disclosure rate of 42%(95%CI:28%,57%)was observed, accompanied by a heterogeneity of 97%. Similarly, amongst those where both parents were infected with HIV, an overall disclosure rate of 39%(95%CI:22%,59%) was reported alongside a heterogeneity of 98%.The variations in different outcome indicators are illustrated in Figure 3a, 3b, 3c, 4a and 4b.

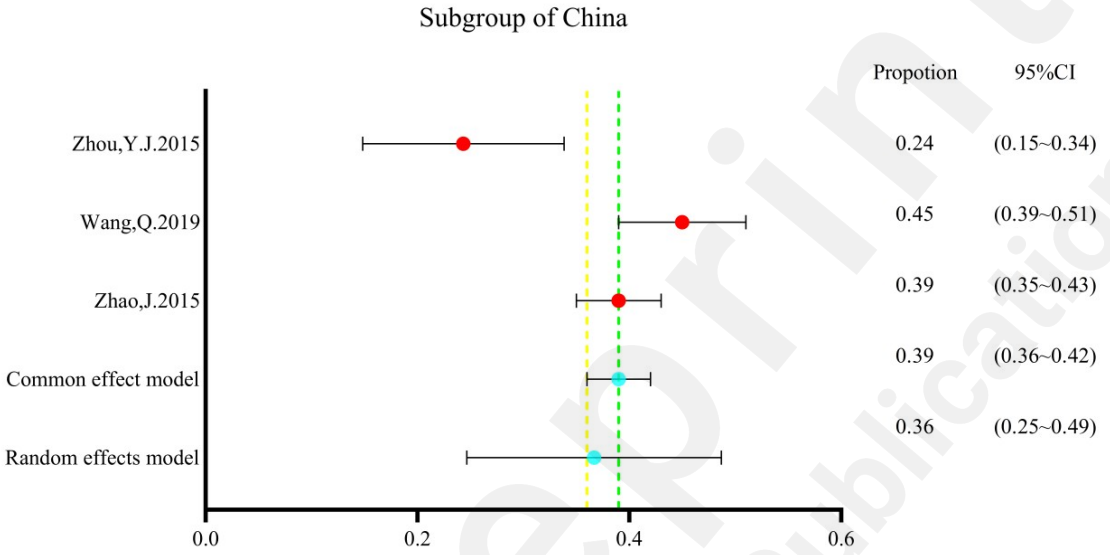

Figure 3a

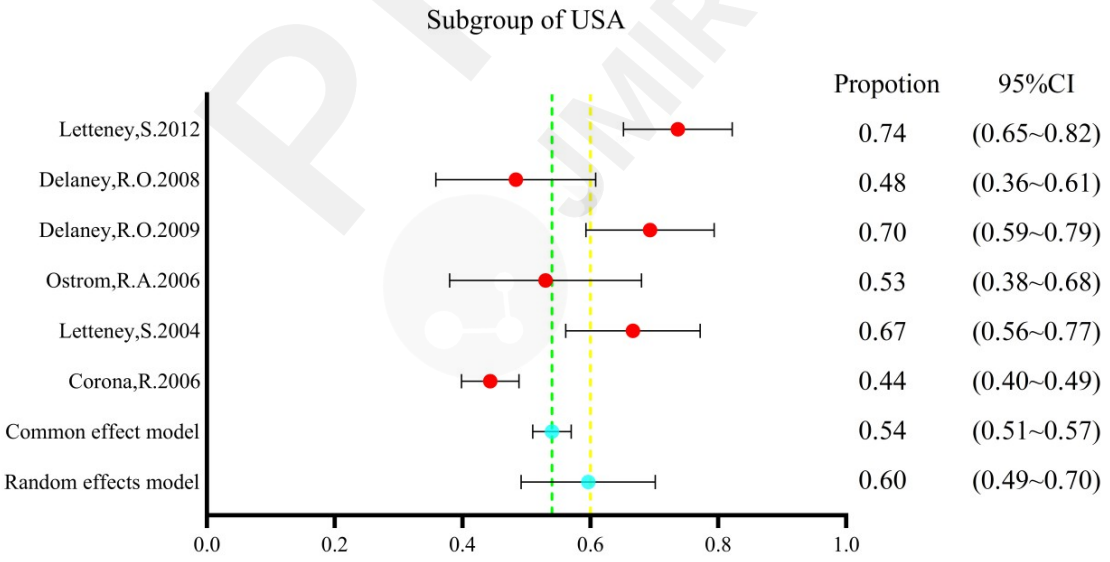

Figure 3b

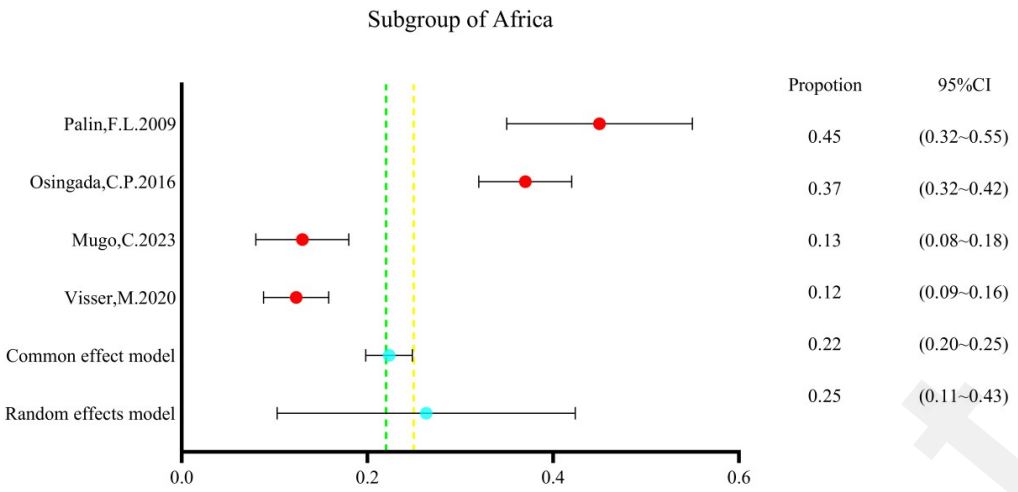

Figure 3c

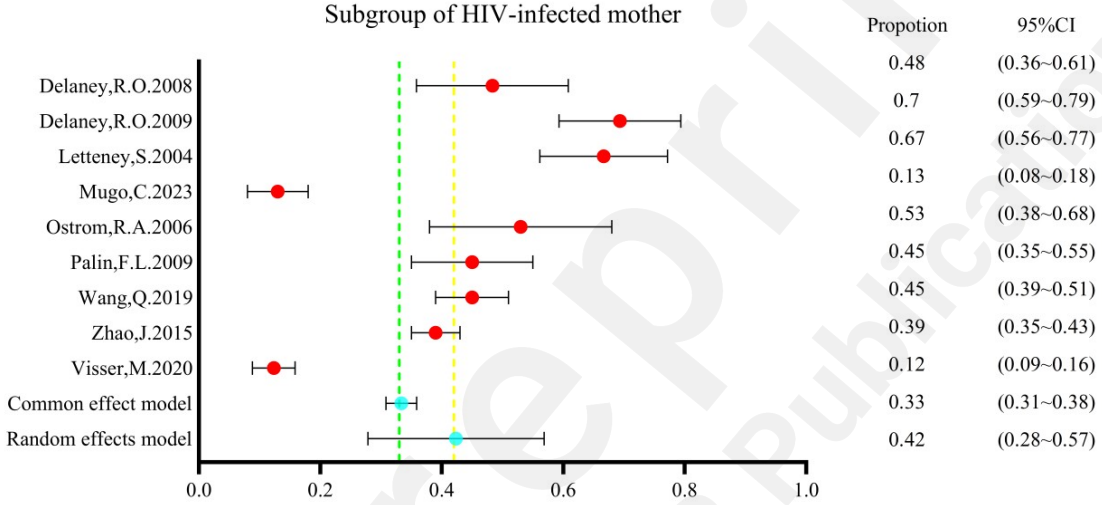

Figure 4a

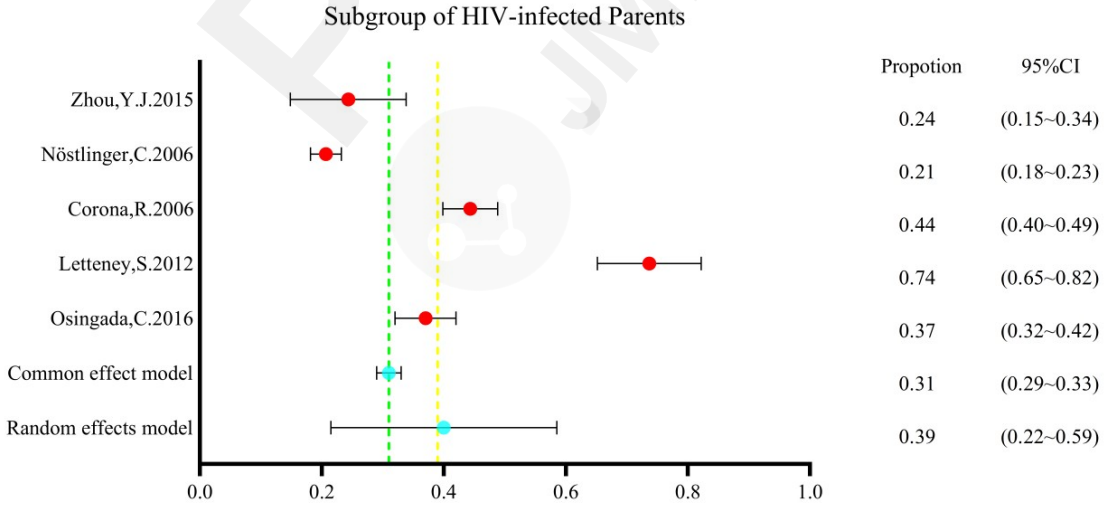

Figure 4b

Risk of Bias and Applicability

There was no obvious asymmetry in the funnel plot visual results of each study. The results of Eggers linear regression analysis are shown in Table 3, indicating no publication bias. In sensitivity analysis, inter-study heterogeneity remained high after removing one paper with a quality score ≤6. This suggests that the paper has no effect on the aggregate effect size.

Table 3 Results of publication bias test for each study outcome

Eggers' test	Disclosure rate
t	2.31
P	0.0395

Discussion

In this meta-analysis, we found that the global average rate of disclosure by HIV-infected mothers to their children is only 41 % (between 30 % and 52 % within a 95% confidence interval). This finding not only highlights significant differences in disclosure rates across regions and family contexts, but also points to a global problem of suboptimal HIV disclosure that needs to be addressed.

Results of the subgroup analyses have found that the HIV status disclosure rate was higher in the U.S. (60%) compared to China (36%) and Africa (30%). The reasons behind the trend of significantly higher disclosure rates in economically developed regions can be multidimensional(28). Economically developed regions not only have better education systems and healthcare facilities that enhance public awareness of HIV, but also provide abundant resources and support for infected people, thus contributing to higher disclosure rates(29). In addition, their more open and inclusive socio-cultural environment may lessen discrimination against people living with HIV, creating a more favourable social climate for disclosure(30). Residents of economically developed regions also tend to enjoy higher levels of economic well-being, which reduces the financial burden of accessing healthcare services and psycho-social support(31). Furthermore, these regions are likely to have more robust legal and policy frameworks that protect the rights of people living with HIV and encourage disclosure behaviors(32). In contrast, economically disadvantaged areas may face a lack of educational resources, limited healthcare resources, and insufficient social support, all of which may discourage HIV-infected individuals from informing their families about their condition(33,34). Economic pressures and social discrimination may also pose additional concerns and barriers to disclosure for people living with HIV in these areas(35).

Our study also showed that families with only mother being infected with HIV had a slightly higher disclosure rate than families with both parents being infected with HIV. The primary modes of HIV transmission encompass sexual, bloodborne, and mother-to-child routes. In households where the mother is the sole HIV-infected individual, the predominant risk of transmission revolves around

mother-to-child transmission(36). Maternal transmission can occur during pregnancy, childbirth, and breastfeeding. Consequently, families with only an HIV-infected mother are more inclined to disclose their infection status to their children.Also at the family level, one study in the United States found that HIV-positive mothers wanted to play a leading role in deciding whether to disclose their HIV status to their children(16). A number of studies have indicated that single and widowed mothers are more likely to disclose their children, to varying degrees, than mothers who are partnered or married(27).

Principal Findings

Findings of the study revealed that HIV status disclosure of women was low and multidimensional measures were needed to effectively address this challenge. These measures may include, but are not limited to, upgrading the standard of education and medical care in less economically developed areas, strengthening public health promotion, improving social attitudes towards people living with HIV, and formulating and implementing supportive policies and laws. These measures can promote a non-discriminatory social environment that ensures that all infected people receive the necessary support and respect, gradually narrowing the gap in HIV disclosure rates between different regions. More research and interventions are needed to promote HIV status disclosure and reduce HIV-related stigma and discrimination through social support, mental health services, and educational interventions.

Strengths and Limitation

Disclosure reduces the side effects of HIV transmission, reduces discrimination, and establishes normal and healthy family, parent-child and social relationships. It promotes the mental health of vulnerable people. This would be critical not only for family dynamics, social attitudes, and individual mental health(37,38), but also for improving HIV treatment adherence(39) and quality of life (40). Furthermore, our study suggests that despite some heterogeneity, the frequency and quality of disclosure needs to be improved with appropriate support and interventions.

In this review, the literature included covered a broad time horizon, but the potential impact of time on disclosure rates was not explored in depth, which may limit the comprehensiveness of the findings. In addition, there are significant differences in the sample size of the included literatures, which may have a certain impact on the stability and reliability of the research results. This meta-analysis focused on global rates of disclosure and only subgroup analyses were performed for regional differences and household infection status. However, the study not aimed to explore in detail other factors that may affect the rate of disclosure, which to some extent limited the depth and breadth of the study. Therefore, this study has some limitations in terms of methodology and

interpretation of results.

Future Perspective

The creation of more equitable and empowering social environments and larger roles for women's organizations in HIV responses remains an unmet objective in many countries(41). Most of the current researches are cross-sectional or cohort studies, with overall low rates of disclosure. This is opposite to the objective of disclosure advocated by the World Health Organization (WHO). Our study provides important insights into the global issue of HIV status disclosure among HIV-infected mothers.

Conclusion

Findings highlight the need for further research and policy development to support the decision-making of HIV-infected mothers in disclosing infection status to their children, which would have important policy and clinical implications for promoting HIV care of HIV-infected mothers and her family.

Acknowledgments

Conflict of Interest

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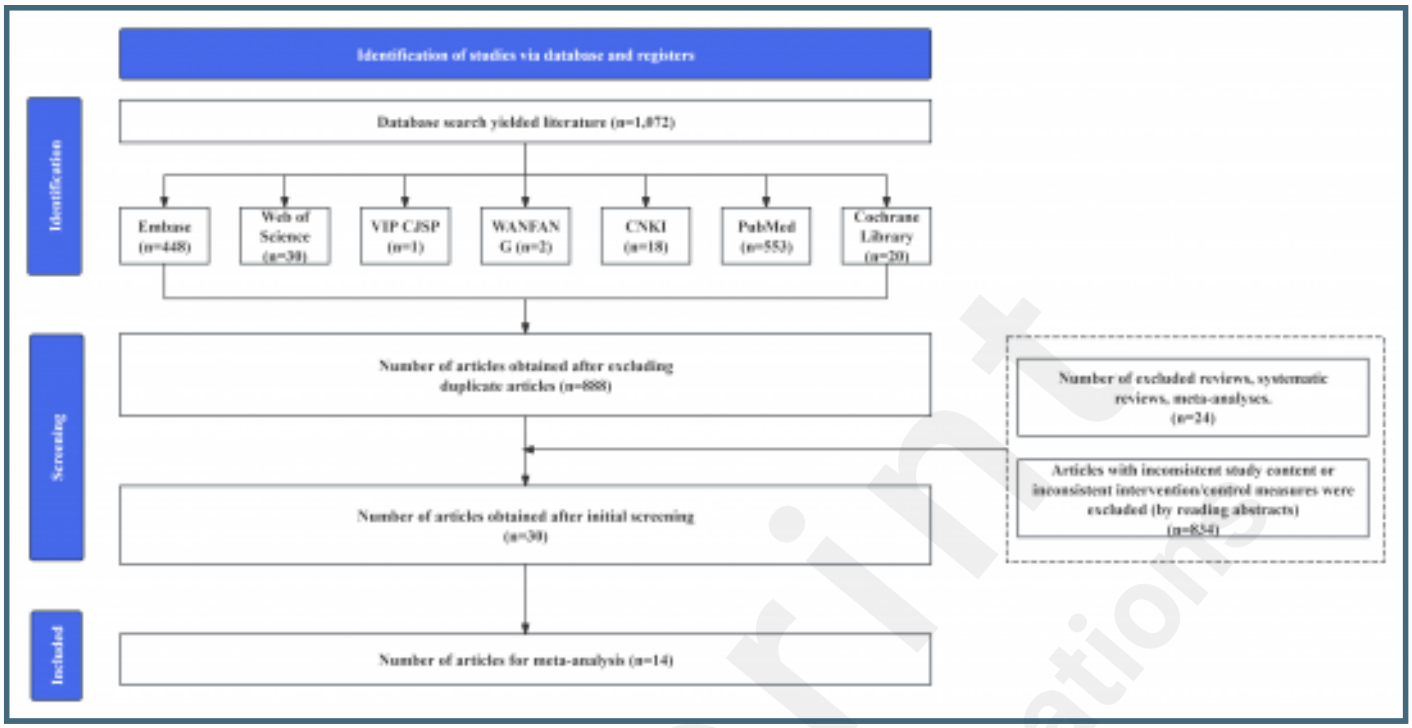
Supplementary Files

Untitled.

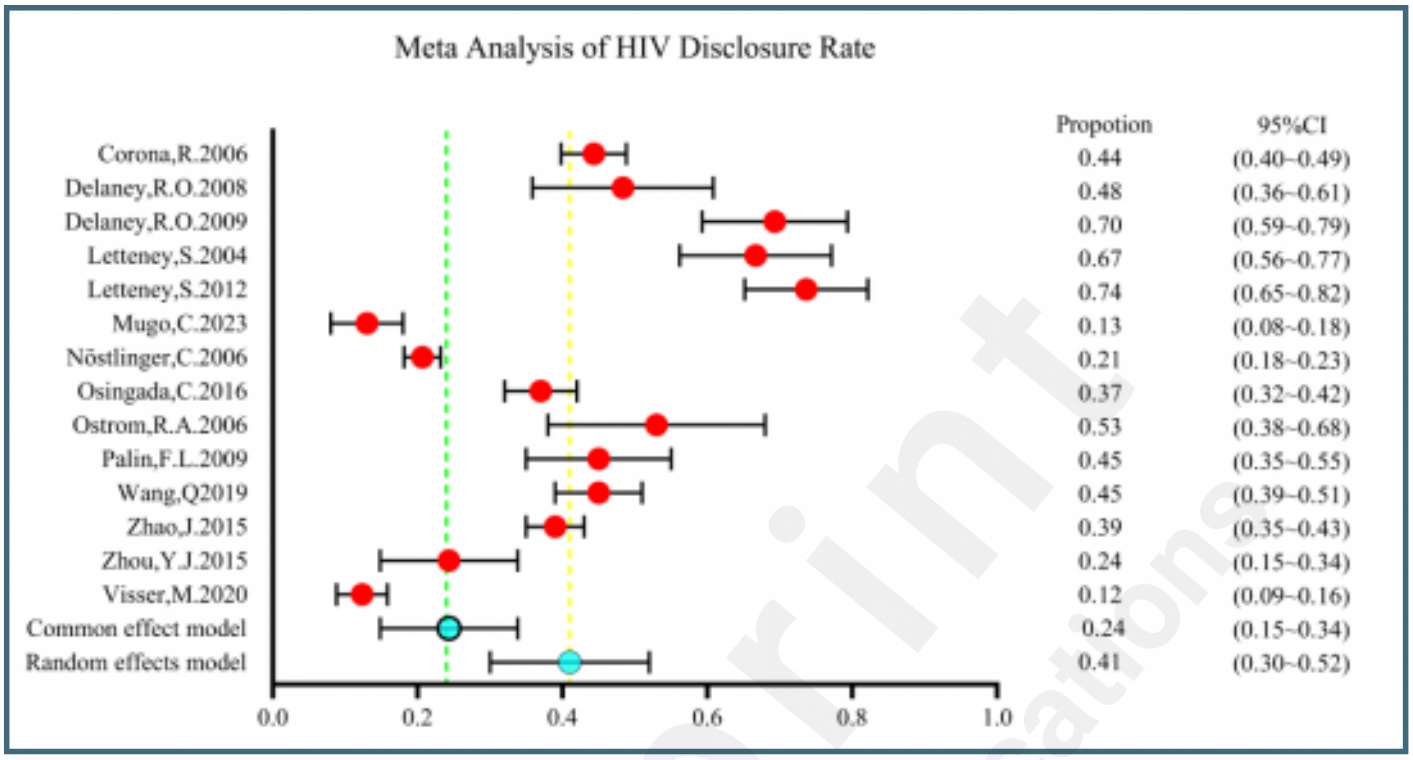


Figures

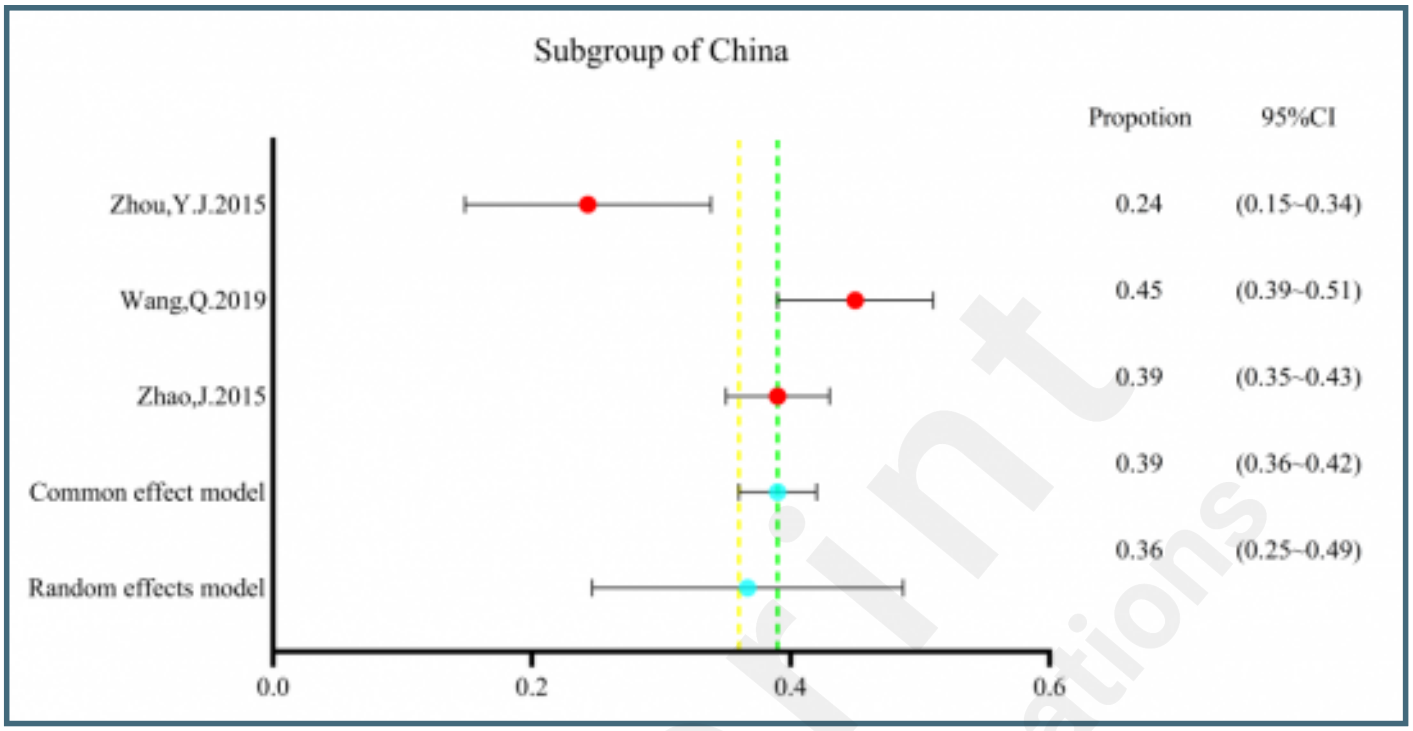
Untitled.

Ref No.	Author[1]	Country/Region	Study size	Outcome (Disclosure)
1	Corona, R.2006	USA	453	200
2	Delaney, R. O.2008	USA	66	32
3	Delaney, R. O.2009	USA	90	63
4	Letteney, S.2004	USA	88	59
5	Letteney, S.2012	USA	101	75
6	Mugo, C.2023	Nairobi, Kenya	205	26
7	Nöstlinger, C.2006	European	1094	226
8	Osingada, C. P.2016	Kampala,Uganda	344	127
9	Ostrom, R. A.2006	USA	45	24
10	Palin, F. L.2009	South Africa	103	46
11	Wang, Q.2019	Guangxi,China	292	132
12	Zhao, J.2015	Henan,China	511	198
13	Zhou,Y.J.2015	Guangxi,China	93	22
14	Visser, M.2020	South Africa	405	50

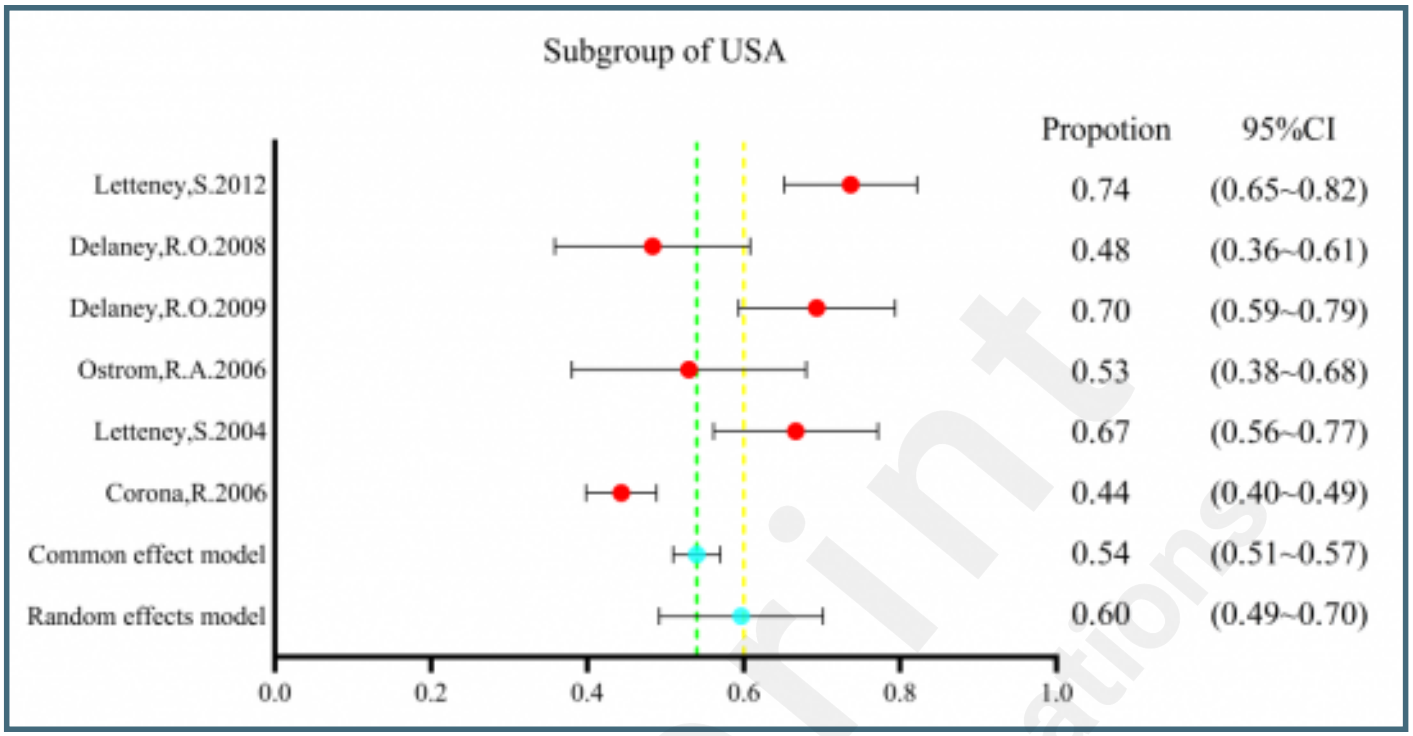
Metanalysis of disclosure rate.



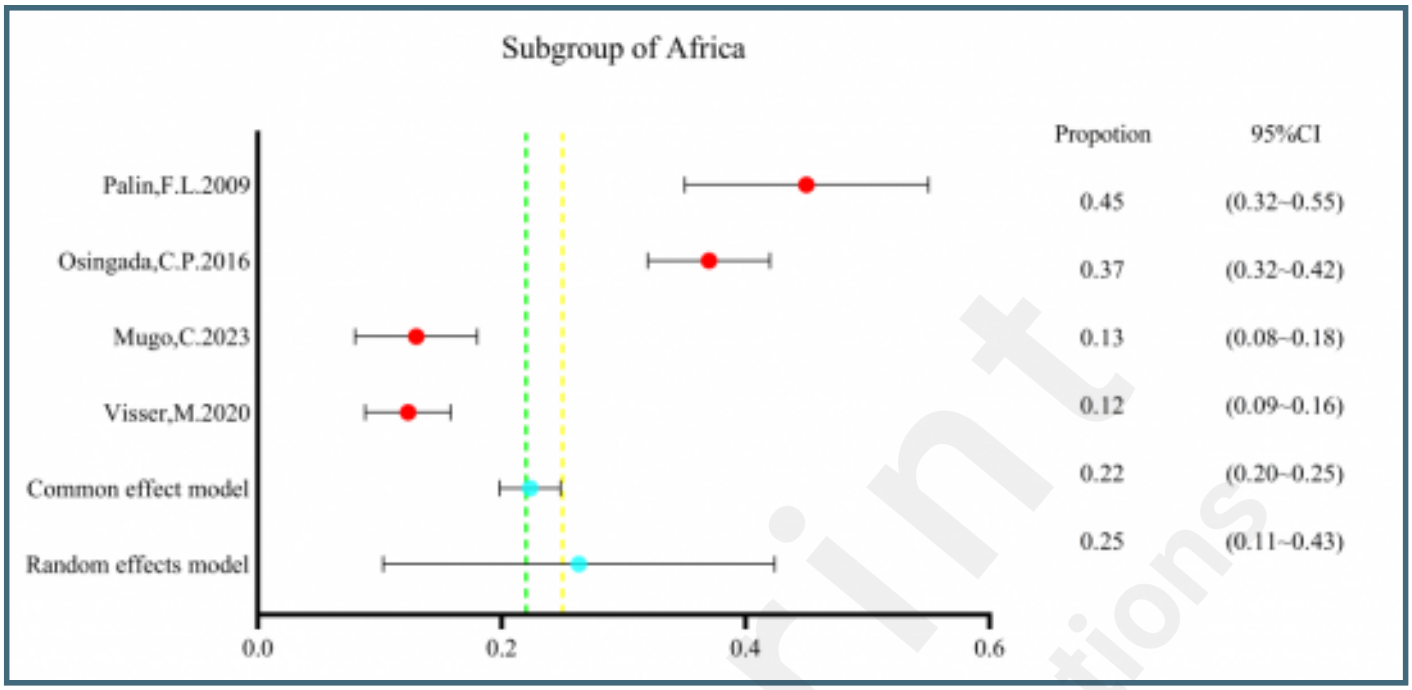
Meta-analysis of disclosure rate of China.



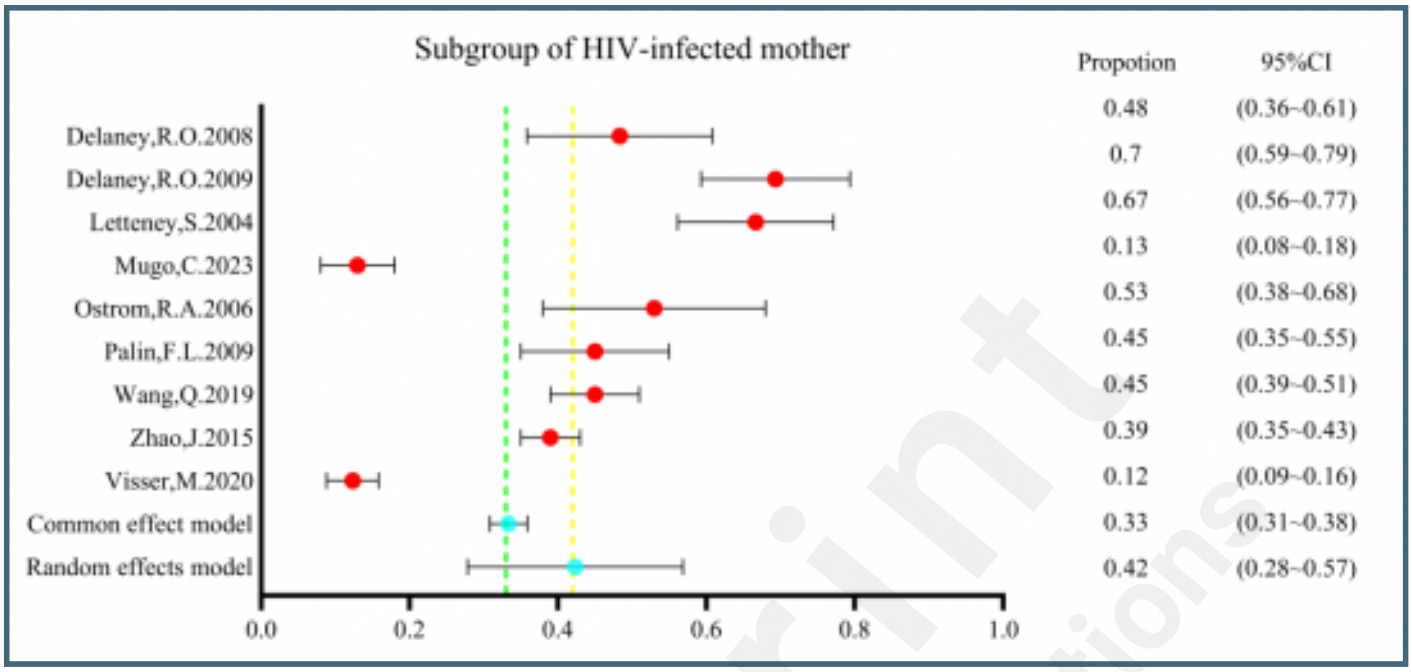
Meta-analysis of disclosure rate of USA.



Meta-analysis of disclosure rate of Africa.



Meta-analysis of disclosure rate of HIV-infected mothers.



Meta-analysis of disclosure rate of HIV-infected parents.