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## Economic Burden of HIV/AIDS upon Households in Nepal: A Critical Review

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### Abstract:

Thousands of people are infected with HIV/AIDS in Nepal and most of them are adults of working age. Therefore, HIV/AIDS is a big burden in Nepal. This review was conducted to find the existing knowledge gap about the economic burden of HIV/AIDS at the household level in Nepal, the extent of economic burden exerted by the disease, and to provide policy recommendations. It is concluded that there was a considerable knowledge gap about the issue, and the economic burden exerted by HIV/AIDS was big enough to push the affected households into poverty. It is suggested that more studies need to be conducted to fill the knowledge gap. Similarly, Government of Nepal and other organisations working in the field of HIV/AIDS need to provide economic supports (e.g.- support for travel costs) to the HIV positive people and need to increase the awareness level among general population for reducing stigma and discrimination, and reducing economic burden on them.

**Keyword:** Economic Burden; HIV; Household; Nepal

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## Introduction

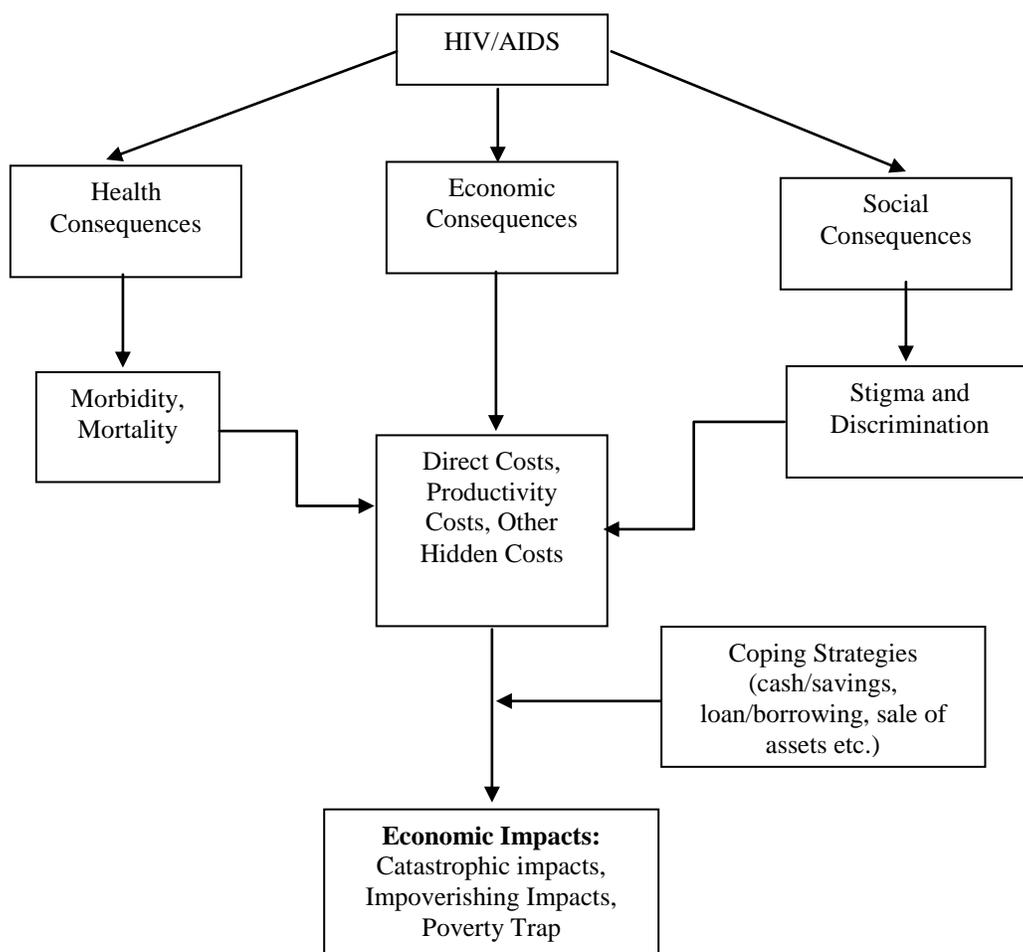
### Economic Burden of HIV/AIDS

Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) has health, economic and social consequences. HIV/AIDS causes health consequences resulting to the morbidity and mortality of infected people [1,2]. People with advanced HIV status are vulnerable to infections and malignancies, due to their poor immune system, called ‘opportunistic infections’. Many of the opportunistic infections occur during the advanced condition of HIV and can be fatal [3]. Increased adult morbidity and mortality due to HIV/AIDS are likely to have important consequences for households, communities and health systems [4]. The death of a HIV positive individual results in a permanent loss of income from less labour on the farm, lower remittances from jobs, costs associated with the funeral and mourning, and a possible removal of children from school in order to save on

educational expenses and to increase household labour and income, resulting in a severe loss of future earning potential for the family [5]. Therefore, the health consequences of HIV/AIDS have an economic impact on the household.

The HIV/AIDS-affected households need to pay a substantial amount of money for the care and treatment of their ill family members [6]. The disease affects the earning capacity of the person and other members of the households too. The HIV positive person may be very weak and may be absent from work or may lose their job due to the illness [7]. The working time of household members may be shifted from productive activities to the care of the sick family members, and thus household income declines further [8]. Thus, the economic consequences can be divided into- direct costs, productivity costs and other hidden costs (e.g. – loss of income).

Figure 1. HIV/AIDS and its possible consequences



(Source: Literature reviews)

HIV/AIDS exerts social impacts and consequences too. HIV/AIDS is perhaps the most stigmatized disease in the world [9]. The disease is more prevalent in female sex workers, the clients of sex workers, injecting drug users and men who have sex with men (MSM) and it is often seen as a disease directly linked with personal behaviour. Therefore, people infected with HIV/AIDS face stigma and discrimination [10]. Stigma and discrimination in HIV/AIDS may result in either not seeking treatment [11] or seeking treatment far from the home where the patient is not known by the health care professionals and others [12]. This behaviour also has economic consequences because not seeking treatment means premature mortality and seeking treatment far from home means increased costs for the HIV-affected household. People living with HIV/AIDS (PLHA) might lose jobs due to stigma and discrimination from employers if known to them [13,14]. Rejection, isolation, less support from family, relatives, neighbours, friends, and community are also another consequence of the stigma and discrimination related to HIV/AIDS [13, 15]. Therefore, these social consequences also have an economic impact on the household.

Households use a range of strategies to cope with the burden of illness (for both treatment costs and productivity losses) [16]. The immediate coping method of illness for those households who have cash or savings is to use the available cash and mobilise savings [17, 18]. Another frequently used strategy for those households who do not have cash or savings at all or have an insufficient amount is borrowing from family and friends or taking loan from money lenders, or sale of assets [18]. The effect of loans on households can be severe. Some studies show that households remain in debt for a considerable time after the illness, which created the debt [19]. If assets like land and livestock are sold by a poor household, they put the household into a vicious circle of poverty [16]. Other strategies for dealing with the direct costs of illness include diversifying income by engaging in activities other than their normal work or selling their labour [18]. In relation to coping with the productivity costs of illness, tasks are re-allocated among household members (intra-household labour substitution), in some cases external labour may be hired to take on the responsibilities of the ill household members, and children may be taken out of school [20]. Intra-household labour substitution may have adverse consequences particularly when children are removed from school to take on the work activities of a sick parent [21].

In summary, HIV/AIDS is a disease, which has health, economic and social consequences. Thus, it not only affects the victim, but also affects the households. Morbidity and mortality, income losses (due to direct costs for treatment and reduced productivity), and stigma and discrimination are the

health, economic and social consequences of HIV/AIDS respectively. The end impact of all these consequences is 'economic'. This means that all these consequences affect the income, expenditure and savings of HIV/AIDS affected households. These consequences finally push the HIV/AIDS affected households into poverty, which can be classified as a catastrophic, impoverishing and poverty trap impacts.

Findings of the previous studies are evident that HIV-affected households generate relatively lower household income than HIV-unaffected households [22, 23]. HIV-infected people are compelled to stop their employment or business due to their illness [7]. The burden of treatment is significantly greater in HIV-affected households than HIV-unaffected households. This burden increases as the PLHA decline in health and that produces an even greater impact on the household [6, 23]. The households have to spend a higher proportion of their monthly income on the care and support of PLHA [24]. The long-term treatment for HIV/AIDS can have lifelong financial implications on HIV-affected households [25].

Health insurance is either unavailable for HIV-infected people in developing countries [24] or people are not aware of health insurance [26]. Therefore, out-of-pocket payment for health care is widely used by HIV-affected households in developing countries. In case of Nepal, 81.4 % of total health care costs in 2012 were contributed out-of-pocket from households and the rest of the costs (18.6%) were contributed by the government, private companies and donors [27]. This also includes the health care of HIV/AIDS in Nepal. Moreover, there is no social security (e.g. - allowances) in Nepal to the PLHA.

### **HIV/AIDS in Nepal**

The first case of HIV/AIDS was reported in 1988 in Nepal. After that the nature of the HIV epidemic has gradually moved from being a 'low prevalence' to 'concentrated epidemic' [28]. In 2014, an estimated 39,249 people were living with HIV/AIDS and an estimated 2,576 people died due to the disease. An estimated number of 1,493 people were newly infected by HIV/AIDS and HIV prevalence rate among adult population was 0.02% [29]. However, the total reported HIV cases were 25,838 as of December 2014. According to the reported cases, 88 % of people living with HIV/AIDS were between the working age of 15-49 years and the majority of them were male (63%) [30]. The above evidences suggest that HIV/AIDS is a big burden in Nepal because it is concentrated on thousands of working age adults.

Despite considerable efforts from donors, government, non-governmental organisations (NGOs), and international non-governmental organisations (INGOs); people living with HIV/AIDS have to pay a significant amount of money for their treatment and care. PLHA need to pay travel costs, most

diagnostic test costs, medicine costs (except ART), lodging and food cost. The government provides only Cluster of Differentiation 4 (CD4) test services and ART medicines free of cost. Wasti *et al.* reported that PLHA in Nepal faces financial constraints for HIV/AIDS treatment. Their report states that PLHA are facing difficulty to manage out-of-pocket expenses like diagnostic test costs, additional costs incurred through travel, nutritional and other user charges [11]. Moreover, CD4 count and Facs calibre sites were limited only in 28 treatment centres in Nepal, which compelled PLHA to travel further for CD4 count tests from time to time. Wasti *et al.* highlighted distance as a major problem because treatment centres were concentrated in urban areas or town centres. PLHA in the rural hill areas are dying without getting treatment because of the lack of travel costs. If the PLHA has to go to Kathmandu for CD4 tests, the travel costs are six times higher than the average daily income of many Nepalese people [11].

HIV/AIDS is one of the biggest burdens of diseases in Nepal as thousands of adults are affected by it. The disease has multiple consequences (e.g. - health, economic and social). Therefore, it is an important public health issue. However, it was assumed that there were only limited numbers of relevant studies conducted and no one knows how many published or unpublished papers are in Nepal on this issue till date.

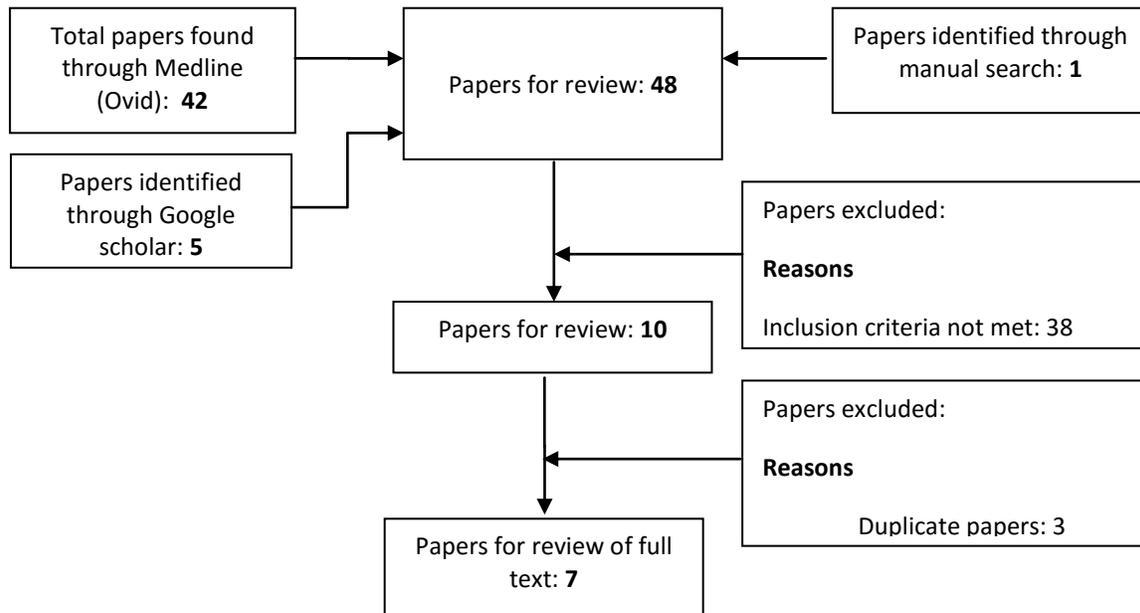
Moreover, there was no review paper published on this topic which could be useful to the policy makers at the government level and other stakeholders working in the field. Likewise, there was no idea among public health researchers about the existing knowledge gap on economic burden of HIV/AIDS in Nepal.

This review is conducted to find the existing knowledge gap about the economic burden of HIV/AIDS, extent of economic burden exerted by the disease at the household level, and to provide policy recommendation to the Nepalese Government for the welfare of HIV positive people. Therefore, it is believed that the results of the review will be helpful to the public health researchers, policy makers and other stakeholders working in the field of HIV/AIDS in Nepal.

### Methodology

This paper is prepared by reviewing published and unpublished literature concerning the economic burden of HIV/AIDS in Nepal. Based on the consequences of HIV/AIDS, the economic burden was sub-divided into five components namely- direct costs, productivity costs, economic consequences of stigma and discrimination related to HIV/AIDS, coping strategies, and catastrophic and impoverishing impacts.

Figure 2. Flow diagram of the literature selection process for the review study



Five different search strategies were used to find the studies related to the economic burden of HIV/AIDS. The first search strategy used in the study was the direct costs for HIV/AIDS in Nepal. The second was studies related to productivity costs and the third one dealt with the economic consequences of stigma and discrimination. The fourth was the coping strategies and the fifth related to the catastrophic and impoverishing impacts due to out-of-pocket payment.

The literature was searched in the Medline (Ovid) search engine by using different search words from the records ranging from 1990 to Week 2 September 2015. But, the search results were limited by full-text and English. However, Google (scholar) search and manual search were also carried out to find the additional studies for review.

The major search words used to search the literature were- "HIV" or "HIV/AIDS" or "human immunodeficiency virus"; "cost" or "economic burden" or "socioeconomic impact" or "economic impact"; "expenditure" or "health expenditure" or "economic consequence"; "financial impact" or "financial burden" or "productivity loss" or "productivity cost" or "morbidity"; "work productivity" or "labour productivity" or "days lost"; "absenteeism" or "presenteeism" or "disability"; "coping strategy" or "strategy to cope" or "coping measure"; "catastrophic" or "catastrophe" or "impoverishment" or "impoverishing"; "stigma" or "discrimination"; and "Nepal".

While combining all the relevant search words from the aforementioned search strategies, a total of 42 studies were retrieved from Medline (Ovid); a total of five studies were found from Google scholar, and one study was found from manual search. After checking the relevancy, a total of seven studies were selected for the review.

The inclusion criteria for the literature were – the research which is conducted on HIV/AIDS in Nepal and related to direct costs, productivity costs, economic consequences of stigma and discrimination, coping strategies (financial), catastrophic and impoverishing impacts, the article which full text is available, published after 1990 to Week 2 September 2015, and in English.

The exclusion criteria for the literature were the research articles whose full text were not available, not related to Nepal, not related to the household level of economic burden (or related to the burden at national level), not related to economic consequences of stigma and discrimination, published before 1990, and in other languages than English.

After searching the studies, we synthesised the important information from each study about the research methods, sample size, study location, and main findings. We contrasted and compared these findings based on the similarities, differences and represented critically in this paper.

## Results

A total of seven studies were selected based on the criteria set above for the review. Among them, three studies were related to direct costs of HIV/AIDS treatment [31-33], one of them also touched a little about the productivity costs of HIV/AIDS [33]. Other four studies were related to the economic consequences of stigma and discrimination associated with HIV/AIDS [13-15, 34]. However, there was no study which investigated the coping strategies, catastrophic and impoverishing impacts of HIV/AIDS in Nepal. Details about the results and findings of the review are presented below.

### Direct Costs

While looking at the literatures related to direct costs of HIV/AIDS, only three studies were found. Two studies were from published articles [31, 32] and one from unpublished MSc thesis [33]. Puri *et al.* and Thapa did cross-sectional survey [32, 33], but research method is not clear in the study by Pradhan *et al.* [31]. Puri *et al.* conducted studies on nine cities of Nepal about the costs of sexual and reproductive health in 2006 with 1,669 respondents [32]. Thapa conducted small survey with 50 respondents who came to take anti-retroviral medicine (ART) at Teaching Hospital, Kathmandu in 2007 [33]. Pradhan *et al.* calculated costs of care for children affected by HIV/AIDS, but their study is silent about sample size [31].

Puri *et al.* reported the out-of-pocket costs for HIV/AIDS treatment for a three month period was only NRs 541 (US\$ 7.5) (NRs 180.3/month) [32]. Thapa found more than double the direct costs to visit treatment centre than reported by Puri *et al.* [32, 33]. She found the direct costs of NRs 404 (\$7.27) per visit to get ART medicine [33]. Considerably lower treatment costs in Puri *et al.*'s study than Thapa's study may be due to two reasons- 38 % of respondents in Puri *et al.*'s study did self-treatment by visiting local pharmacy and they included many cities in their study (geographical variations) [32, 33]. However, both of the studies did not include costs for the accompanying person while visiting the treatment centres, only concentrated in the cities and excluded the remote rural parts of the country where the HIV positive people need to pay up to six times of their daily wage for travel costs for their treatment [11]. Moreover, these studies did not include diagnostic costs while calculating direct costs of treatment [33]. Unlike the above two studies, a study by Pradhan *et al.* reported the actual care costs for HIV-affected child per month from societal perspectives- NRs 6,763 (US\$ 93.9), NRs 9,269 (US\$ 128.7) and NRs 42,602 (US\$ 591.7) in community based care, home based care and comprehensive institutional care respectively [31]. It should be noted that the study by Pradhan *et al.* is completely different from Puri *et al.* and Thapa because it employs three different models and the

costing was done from societal perspectives [31-33]. They did not separate costs of HIV/AIDS treatment in their study. Therefore, their findings are not directly comparable to the other two studies, although they are related.

The studies reviewed above shows that there are only a limited number of studies assessing direct costs of HIV/AIDS treatment in Nepal. These studies [32, 33] did not include all the costs components for HIV/AIDS treatment and only concentrated in the urban areas. Therefore, if the costs calculations were done properly, the direct costs for HIV/AIDS treatment would have been considerably higher than reported in these studies, although the studies reported the costs which are big enough to push HIV-affected households into poverty.

### **Productivity Costs**

There has been no study to measure the productivity costs of HIV positive people in Nepal. However, Thapa tried to calculate the value of time lost while visiting treatment centres to get ART medicine by HIV positive patients in Kathmandu valley (NRs 105.2 or US\$ 1.5 per visit) [33]. The study did not investigate the actual productivity costs of HIV/AIDS in Nepal. Here, actual productivity costs mean costs incurred due to ill health, which include monetary value of absenteeism and presenteeism caused by HIV/AIDS. Therefore, actual productivity costs due to HIV/AIDS among HIV positive people is still unknown in Nepal.

### **Economic Consequences of Stigma and Discrimination**

As there were no proper studies investigating the economic consequences of stigma and discrimination related to HIV/AIDS in Nepal, all the studies reporting some sorts of economic issues are reviewed in this paper.

There were four studies which touched the economic consequences of stigma and discrimination related to HIV/AIDS in Nepal. Three of the studies were focussed broadly on HIV/AIDS related stigma and discrimination in general [13-15] but one study was focussed solely on women's issues related to HIV/AIDS [34]. FHI [34] and FHI [13] conducted interviews with 57 respondents in each study but Rai conducted mixed methods of interviews (with 7 respondents) and literature reviews [15]. However, Nepal and Ross used secondary data which contained information of 80 individuals and 12 focus groups discussions [14].

A study by FHI [13] reported that there was a separation of PLHA from communities and families, loss of employment and restrictions on movement and activities in communities [13]. Moreover, it was reported that HIV positive women were discriminated greatly compared to men and more often faced permanent loss of family support. FHI [34] also reported similar findings. According to FHI [34], HIV positive women were not accepted and supported by their family compared to their husbands who were also HIV positive. Many women faced serious loss of social and economic support from their

family and society. They also found that deteriorating economic conditions with women and their children once their husband died [34]. Similar to these findings, Rai reported that women face a lack of acceptance and support from family members more than their HIV positive husbands. Some PLHA, generally women are forced to leave home after the detection of HIV status. Moreover, most PLHA face the problem of finding work and contributing economically to the household [15]. Nepal and Ross also reported that PLHA were excluded and rejected from home and society which greatly stressed their economic status [14]. Similar to findings reported by FHI [13], they also reported that more than 20 % of PLHA's employment was affected negatively after the detection of the disease [14].

The review found that the study findings are very general and not quantified in numbers or figures (e.g. – percentage). Isolation, rejection, exclusion (from job, family or society), less supports were major forms of stigma and discrimination which had economic consequences on PLHA. Although all PLHA were discriminated, it was found that HIV positive women faced more discrimination and less support from their family and society, which makes them more vulnerable. There is also a need of further study which explores the consequences in detail.

### **Coping Strategies, Catastrophic and Impoverishing Impacts**

The literature review concluded that there were no studies relating to the coping strategies (financial) used by HIV/AIDS affected households. Likewise, there were no studies reporting the catastrophic and impoverishing impacts due to HIV/AIDS in Nepal till the date. Therefore, there is a complete knowledge gap in these economic issues.

### **Conclusion**

The review found that there was insufficient research concerning economic burden of HIV/AIDS in Nepal. Three of the studies assessed the direct costs of HIV/AIDS treatment. Nevertheless, these studies did not include all the components of the direct costs and did not cover rural and remote areas of Nepal. There was no study in Nepal which reported the actual productivity costs caused by HIV/AIDS. There were four studies which slightly touched the economic consequences of stigma and discrimination related to HIV/AIDS in Nepal. There were no studies which explored the coping strategies used by HIV/AIDS affected households. Likewise, there was no study which quantified the catastrophic and impoverishing impacts due to HIV/AIDS. Therefore, it is concluded that there was no research which assessed the economic burden of HIV/AIDS in Nepal covering all the cost components and geographical locations. Thus, there is a big knowledge gap about the burden in the Nepalese context and we strongly

recommend conducting further studies which can explore all the issues relating to the economic burden of HIV/AIDS in depth covering all geographical locations.

While looking at the extent of economic burden of HIV/AIDS at the household level, it is concluded that the reviewed studies under reported the direct costs as they did not include all the components (e.g. - diagnostic costs, costs for accompanying person) while calculating. They did not calculate the productivity costs (value of absenteeism and presentism due to HIV/AIDS) too in their studies, which also share big proportion of economic burden. Therefore, it was concluded that the economic burden exerted by the disease would have been very high if they calculated the burden by including all the cost items. However, the review findings and available evidences suggest that the economic burden of HIV/AIDS is big enough to push the HIV-affected households into poverty in Nepal.

We cannot recommend many policies from this review as there were limited studies which could not provide sufficient knowledge about the economic burden. However, based on the available studies and evidences, the review concluded that the economic burden of the disease is high at the household level. Therefore, the Government of Nepal and other organisations working in the field of HIV/AIDS need to focus on reducing the economic burden by providing economic supports (e.g. – allowances for treatment costs, support for travel costs) to the PLHA and increasing awareness level of the general people about the HIV/AIDS through trainings and other programmes (like radio programme) for reducing stigma and discrimination, and thus reducing economic burden on them. Moreover, female PLHA need more attention and supports than their male counterparts as they were more discriminated from their family and society.

#### **Limitation of the Paper**

This review paper is mainly based on the published studies available online (Ovid-Medline and Google scholar) and very few unpublished studies (available from manual search). There might be other unpublished studies too which we could not manage to find manually and did not include in this study. This might limit the findings of our study.

#### **Conflict of interest:**

The authors have no conflict of interest arising from the review study.

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