

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Is there lower utilization of hospice care services during end-of-life care for people living with HIV? A population-based cohort study
AUTHORS	Chan, Shang-Yih; Lai, Yun-Ju; Ko, Ming-Chung; Chen, Yu-Yen; Tsai, Yi-Fan; Hsu, Li-Fei; Ku, Po-Wen; Chen, Li-Jung; Chuang, Pei-Hung; Chen, Chu-Chieh; Yen, Yung-Feng

VERSION 1 – REVIEW

REVIEWER	Leibowitz, Arleen University of California Los Angeles, Luskin School of Public Affairs
REVIEW RETURNED	08-Nov-2021

GENERAL COMMENTS	<p>HIV infection associated with lower utilization of hospice care services during end-of-life- treatment: A nationwide cohort study</p> <p>This paper uses data from the Centers for Disease Control HIV Surveillance system in Taiwan and from the Taiwan National Health Insurance Research Database to examine the use of Hospice Services among People living with HIV and among a matched set of controls who died.</p> <p>The analysis is appropriate and the writing is clear, with one exception. The authors should clarify that the non-HIV control sample was selected from among persons without HIV who died. Inserting that caveat on p. 9 line 49, page 13 line 30, page 15 line 19 and 55, page 16 line 12., would help clarify that the hospice use equation is being estimated among people who died. A short description of how the last year of life was determine would also be helpful.</p> <p>The paper states that this is the first and largest study to compare the use of hospice services for PLWH and persons without HIV. However, it is not the first to examine determinants of hospice use among terminal PLWH. See Leibowitz AA, Tan D, Gildner JL. The Effect of Hospice on End-of-Life Costs for Terminal Medicare Patients with HIV in the journal Inquiry in 2020. The omission of this reference is the reason for my score on References. This paper finds similar results to those reported here. For example, cancer patients were more likely to use hospice and African Americans significantly less likely to use hospice. That paper did not find a significant effect of gender. It would be interesting to directly test the interaction of gender and HIV in the hospice use equation since women represent such a small share of decedents.</p>
-------------------------	--

REVIEWER	Lyon, Maureen George Washington University School of Medicine and Health Sciences, Pediatrics
REVIEW RETURNED	10-Nov-2021

GENERAL COMMENTS	<p>This is a nationwide cohort study conducted in Taiwan, entitled "HIV infection associated with lower utilization of hospice care services during end-of-life treatment: A nationwide cohort study" (MS # bmjopen-2021-058231).</p> <p>This is a very important study examining differences in use of hospice care services among HIV positive adults compared to HIV negative adults, using scientifically rigorous methods to examine a high-quality nationwide data set from the National Health Insurance Research Data base. Investigators used strict HIV diagnostic criteria. The data set are further strengthened by the fact that insurance is not a barrier to care services in Taiwan, as it is in many other countries.</p> <p>Investigators highlight the potential importance of their findings with respect to disparities in health care utilization. Although their data set could not reveal the reasons for this finding, investigators provide possible explanations based on previous research in which fear of disclosure of HIV status to others because of HIV stigma or discrimination on the part of hospice providers who report not feeling competent to treat complex HIV positive persons at the end-of-life and so do not accept HIV positive persons into hospice care. They correctly note this requires further study.</p> <p>Investigators report the limitations of their findings in detail. Important potential explanatory variables were not in the data set, such as individuals' religious beliefs or patient preferences with respect to hospice care. They also note that study findings may not generalize beyond the Taiwanese context.</p> <p>The title appropriately reflects the content of the manuscript.</p> <p>The abstract is a good summary of the findings and includes all essential elements.</p> <p>Introduction. The introduction notes the gap in knowledge about hospice care utilization among HIV positive persons at the end of life compared to HIV negative persons. The introduction sets up the purpose of the study to examine deaths in hospice from 2000-2018 to determine if there was a gap in hospice services for HIV positive persons compared to HIV negative persons. This is important as hospice care is associated with better quality of life outcomes for patients and is recommended for persons living with HIV.</p> <p>Methods. Sampling strategy. This cohort study used data from the Taiwan centers for disease control HIV Surveillance Database from 2000-2018 for all persons 18 years of age or older. The control group (HIV negative individuals) was selected from the Taiwan National Health Insurance Research Database. Subjects were matched by age and sex. In Taiwan more than 99% of citizens are covered by the National Health program.</p>
-------------------------	--

	<p>Data analysis. The outcome variable was the utilization of hospice care services during the last year of life, determined through patients' medical records. The data analysis is appropriate for the data. Investigators also conducted a sensitivity analysis.</p> <p>Findings. Results are clearly described and very, very important.</p> <p>Ethical Issues Pertaining to Human Subjects. Informed consent was waived for study participants and this was approved by the local Institutional Review Board.</p> <p>The descriptive Tables and supplement are very clear.</p> <p>Discussion and conclusion follow from the data and does include a comprehensive review of relevant literature to compare and contrast their findings with earlier studies.</p> <p>To summarize, study findings demonstrate of persons who died in Taiwan between 200-2018 only 5.76% of persons living with HIV received hospice services during end-of-life treatment, compared to 12.30% of controls. Younger persons living with HIV and males living with HIV were significantly less likely to receive hospice services.</p> <p>Investigators recommend that future hospice programs should particularly target PLWH to increase optimal use of hospice care when dying.</p> <p>This is a very important study in light of the aging of persons living with HIV and the need to increase optimal hospice care services among persons living with HIV during end of life treatment.</p> <p>References. In January 2021 the American Journal of Hospice and Palliative Care published a special issue which had a survey describing attitudes about hospice among HIV positive persons in the United States which the investigators might find of interest.</p>
--	---

VERSION 1 – AUTHOR RESPONSE

Reply to the Reviewer 1 Comments

1: The analysis is appropriate and the writing is clear, with one exception. The authors should clarify that the non-HIV control sample was selected from among persons without HIV who died. Inserting that caveat on p. 9 line 49, page 13 line 30, page 15 line 19 and 55, page 16 line 12., would help clarify that the hospice use equation is being estimated among people who died. A short description of how the last year of life was determine would also be helpful.

Reply 1: We really appreciate your advice. The control group was selected from the Taiwan National Health Insurance Research Database and included those who had never been reported to the Taiwan CDC as HIV-infected cases. The control group was matched for age, sex, and date of enrollment (± 7 days). Ten controls were randomly selected for each HIV patient. To compare the utilization of hospice care services between patients who were HIV-infected and HIV-negative during their last year of life, this study only included deceased PLWH and controls in the analysis. We add this information in the method "The control group was selected from the Taiwan National Health Insurance Research Database and included those who had never been reported to the Taiwan CDC as HIV-infected cases. The control group was matched for age, sex, and date of enrollment (± 7 days). Ten

controls were randomly selected for each HIV patient.^{13 14} All HIV patients and controls were followed until death, or up to December 31, 2018. Data on death events were obtained from the death certificate database of Taiwan.¹⁵ To compare the utilization of hospice care services between patients who were HIV-infected and HIV-negative during their last year of life, this study only included deceased PLWH and controls in the analysis.” Please see Page 10 (third paragraph, line 1-14). The outcome variable was the utilization of hospice care services during the last year of life among PLWH and the control group. This study used the Taiwan National Health Insurance Research Database to determine the utilization of hospice care services during the last year of life between the two groups. We include this statement in the analysis “The outcome variable was the utilization of hospice care services during the last year of life among PLWH and the control group. This study used the Taiwan National Health Insurance Research Database to determine the utilization of hospice care services during the last year of life between the two groups. Hospice care services included hospice inpatient care, hospice-shared care, and hospice home care.¹⁵” Please see Page 11 (second paragraph, line 1-6).

2: The paper states that this is the first and largest study to compare the use of hospice services for PLWH and persons without HIV. However, it is not the first to examine determinants of hospice use among terminal PLWH. See Leibowitz AA, Tan D, Gildner JL. The Effect of Hospice on End-of-Life Costs for Terminal Medicare Patients with HIV in the journal *Inquiry* in 2020. The omission of this reference is the reason for my score on References. This paper finds similar results to those reported here. For example, cancer patients were more likely to use hospice and African Americans significantly less likely to use hospice. That paper did not find a significant effect of gender. It would be interesting to directly test the interaction of gender and HIV in the hospice use equation since women represent such a small share of decedents.

Reply 2: We really appreciate your advice. Leibowitz et al. study found that, of 1,375 terminal Medicare patients with HIV, 338 (24.6%) received hospice care during the EOL treatment. We add this information in the discussion section “Hospice care could improve PLWH’s quality of life during their EOL treatment.⁷ However, there are limited studies evaluating the utilization of hospice care services among PLWH. A retrospective cohort study including 367 HIV patients hospitalized in a large urban safety-net hospital showed that 28% of the patients died during such hospitalization. However, only 6% of the patients were enrolled in hospice.⁹ Another retrospective study involving 1,375 HIV patients in the US found that 24.6% of terminal Medicare patients with HIV received hospice care during EOL treatment.¹⁰” Please see Page 17 (third paragraph, line 1-8).

We evaluated the interaction of gender and HIV on the utilization of hospice care services during end-of-life care in HIV patients and the results showed that the interaction of gender and HIV was not statistically significant ($p=0.821$).

Reply to the Reviewer 2 Comments

1: Discussion and conclusion follow from the data and does include a comprehensive review of relevant literature to compare and contrast their findings with earlier studies.

Reply 1: We really appreciate your advice. Hospice care could improve PLWH’s quality of life during their EOL treatment. However, there are limited studies evaluating the utilization of hospice care services among PLWH. A retrospective cohort study including 367 HIV patients hospitalized in a large urban safety-net hospital showed that 28% of the patients died during such hospitalization. However, only 6% of the patients were enrolled in hospice. Another retrospective study involving 1,375 HIV patients in the US found that 24.6% of terminal Medicare patients with HIV received hospice care during EOL treatment. We add this information in the discussion section “Hospice care could improve PLWH’s quality of life during their EOL treatment.⁷ However, there are limited studies evaluating the utilization of hospice care services among PLWH. A retrospective cohort study including 367 HIV patients hospitalized in a large urban safety-net hospital showed that 28% of the patients died during

such hospitalization. However, only 6% of the patients were enrolled in hospice.⁹ Another retrospective study involving 1,375 HIV patients in the US found that 24.6% of terminal Medicare patients with HIV received hospice care during EOL treatment.¹⁰ Our study followed up 32,647 HIV patients and found that 5.76% of PLWH received hospice care services during their EOL treatment. While comparing with HIV-negative individuals, PLWH had a significantly lower utilization of hospice care services during the last year of life. The findings of our study suggest that hospice care is underutilized among PLWH and it is imperative to increase optimal hospice care services among PLWH during EOL treatment.” Please see Page 17 (third paragraph, line 1-13).

2: To summarize, study findings demonstrate of persons who died in Taiwan between 200-2018 only 5.76% of persons living with HIV received hospice services during end-of-life treatment, compared to 12.30% of controls. Younger persons living with HIV and males living with HIV were significantly less likely to receive hospice services.

Reply 2: We really appreciate your advice. Men living with HIV were significantly less likely to receive hospice services in our study. We also evaluated the interaction of gender and HIV on the utilization of hospice care services during end-of-life care in HIV patients and the results showed that the interaction of gender and HIV was not statistically significant ($p=0.821$).

3: References. In January 2021 the American Journal of Hospice and Palliative Care published a special issue which had a survey describing attitudes about hospice among HIV positive persons in the United States which the investigators might find of interest.

Reply 3: We really appreciate your advice. A previous survey about attitudes toward hospice care among PLWH reported that hospice services were perceived to provide essential relief from pain and symptoms during the EOL treatment. However, fear of stigma and concerns regarding the disclosure of their AIDS diagnosis were major barriers for PLWH when participating in hospice care. We add this information in the introduction section “A previous survey about attitudes toward hospice care among PLWH reported that hospice services were perceived to provide essential relief from pain and symptoms during the EOL treatment.⁸ However, fear of stigma and concerns regarding the disclosure of their AIDS diagnosis were major barriers for PLWH when participating in hospice care.⁸” Please see Page 8 (second paragraph, line 6-10).