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REVIEW ARTICLE

Unsung Heroes: Gay Physicians' Lived Journeys during the HIV/AIDS Pandemic - Addendum

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ABSTRACT

The HIV/AIDS pandemic was a major crisis at the end of the 20th century. A defining moment in the history of health-related infections. It led to the transformation of its proponents, as well as their medical practice. This paper is an addendum to a research paper previously published in SAGE Open in 2019. The previously published paper used data from a study conducted by Jacob, in 2012. The data was gathered using semi-structured interviews with six Canadian gay physicians from different Canadian HIV/AIDS treatment centres. The study aimed to answer the following research question: What are the lived journeys of gay physicians while attempting to treat, care for, and cure/heal their HIV/AIDS patients during the pandemic, from 1981 to 2009? The results deduced from a qualitative and interpretive data analysis, as well as a literature review for the published research paper, suggest that through reflection on their experiences during the HIV/AIDS pandemic, they transformed their personal and professional identities, and rethought their relationship with their patients, as well as their professional, pharmaceutical, and community networks. The addendum, using unpublished information from the study and additional information from a literature review of material published by other proponents after the publication of the paper, aims to substantiate the testimonies of six Canadian gay physicians who fought against the HIV/AIDS pandemic and who advocated for their HIV/AIDS patients. In fact, these results are evidence of an untold and valuable period in medical history. For some, it will serve as a reminder. For others, it will be novel and even foreign. It was a time marked by a major crisis that mobilized gay physicians who were personally and professionally affected by their HIV/AIDS patients, and who were forever transformed by their response to the pandemic.

Keywords: HIV/AIDS, pandemic, epidemic, gay, homosexual, physicians, doctors, journeys, experiences, patients, memoir, testimony.

Introduction

In 2019, my colleague and I published a paper that recounted the lived journeys of gay physicians caring for HIV/AIDS patients during the pandemic (early 1980s to late 1990s, and beyond). The 2019 paper (henceforth the paper), titled *Unsung Heroes: Gay Physicians' Lived Journeys during the HIV/AIDS Pandemic,* was published in the Sage Open journal[1]. The results presented in the paper were based on a study titled *Recours à l'apprentissage expérientiel dans la transformation de la pratique médicale de six professionnels dans le contexte de la pandémie du VIH/sida*[2], conducted in 2012. It explored the following question: What are the lived journeys of gay physicians while attempting to treat, care for, and cure/heal their HIV/AIDS patients during the pandemic, from 1981 to 2009. In addition to the literature review included in the study, the paper added a more recent one that covered the period from 2009 to 2019. The paper provided insights into the personal and professional identities of respondents, as well as their relationships with their HIV/AIDS patients and networks, for instance.

During the process leading to the 2019 paper's publication, we were unable to include all the material from the original study in the paper due to various constraints, such as prescribed word count and paper length restrictions. However, we believe that the unused material remains pertinent today. Also, in keeping with the spirit of evergreening our research, we discovered new material regarding the lived journeys of gay physicians caring for HIV/AIDS patients during the pandemic. Consequently, we decided to include the unused data, from the original study, along with new material from a more recent literature review, into this addendum to give readers access to what was not available to them up to this point. Therefore, the intent of this addendum is three-fold: to provide an overview of the study titled Recours à l'apprentissage expérientiel dans la transformation de la pratique médicale de six professionnels dans le context de la pandémie du VIH/sida[2] and the paper titled *Unsung Heroes: Gay Physicians' Lived Journeys During the HIV/AIDS Pandemic*[1]; to add unpublished data from the original study; and to update the information rendered in the discussion section of the same paper with newly uncovered literature pertaining to gay physicians' lived journeys while caring for HIV/AIDS patients during the pandemic.

Methodology

The addendum is a supplement to the 2019 paper. Considering that the paper is based on the results from the study conducted in 2012, the methodology used for this addendum borrows from their methods of analysis. Consequently, they are succinctly introduced here following the order highlighted above, that is 2012 study, 2019 paper, and 2024 addendum.

A) 2012 STUDY

The results from the 2012 study were achieved through a descriptive, interpretive, and exploratory qualitative case study. This methodology was chosen as it provided access to the global meaning of the physicians' experiences while caring for HIV/AIDS patients in the context of the pandemic. As the HIV/AIDS pandemic was a contemporary event, researchers had access into the physicians' everyday life while interacting with and attempting to treat their patients within the confines of a professional–patient relationship.

A1) Literature review

As its name implies, the literature review was used to gather and review the body of literature pertinent to the research topic[3]. At the time, CD-ROMs were used to search pre-identified words associated with the topic. The comprehensive list of search words included (in English and French), physician, doctor, caregiver, and patient, as well as the words gay, homosexual, human immunodeficiency virus (HIV), and acquired immunodeficiency syndrome (AIDS) to help locate relevant literature from the early 1980s up to the time of the study.

A content analysis methodology was used to help understand the data, and to organized it in a meaningful manner. This type of methodology is often used when little is known in a specific area of study and help with identifying data[4]. The data were analysed using a 'paper and scissor' technique, to detect patterns. A reflexive approach was used to collate statements using an iterative process. Multiple categories, themes and sub-themes emerged. Finally, the information was presented in a narrative format.

The first set of books and autobiographies helped identify the themes needed for the preparation of the semi-structured interview grid and to create the initial conceptual taxonomy, which was used to organize and analyse data from the study. The following are examples of themes: the impact of the arrival of the pandemic on physicians, their patients, their community, and their profession; the emotional intensity of the HIV/AIDS context; the influence and the multiplication of scientific and medical discoveries; the developments in the treatment of opportunistic infections related to the HIV infection leading to scientific, medical, and professional uncertainties; the views physicians held towards sexuality, drug use, and HIV/AIDS; and finally, the modification in the way they practiced medicine, going from a physician-centred practice toward a more patient-centred, and a research-oriented practice.

At the time of the study, only two types of literature pertaining to the topic[2], were available, but none were gay specific. These two types of literature included books (see the following as examples: Rabkin, Remien, and Wilson[5]; Kramer [6]; Guibert[7]; Hodge-Wright[8]; Whitmore[9]; Davis and De Vries[10]; Callwood[11]; Cox[12]; Gélinas-O'Meara[13]; Kavanagh[14]; Monette[15], and Oyler[16]), and autobiographies (see the following as examples: Baxter[17]; Verghese[18]; Zuger[19]; Bayer and Oppenheimer[20]; Boulanger & Thomas[21]; McCoy[22]; Olivier[23]; Scannell[24]; and Selwyn[25]). They served to establish a preliminary understanding of the patients' trajectories, from the onset of the infection to his death. They also provided a vivid account of physicians' journeys from the start of the infection to their patients' death and beyond, including attending their funerals (see Appendix 1 HIV-AIDS Pandemic Trajectory: Three Periods)[1].

By providing more information in the preparation of the interview grid, and the categorization for data analysis, these narratives, and the information they contain, had a positive impact on the study.

A2) Interview protocol

The interview protocol, as well as the data collection, production, and analysis, were conducted according to the case study methodology[26–28]. After the standard procedures for qualitative studies, that is, explanation of the study, interview procedure, and consent form, the second phase of the study began, that is, data collection through interviews. Interviews were conducted either at the physician's workplace (e.g., office) or other private settings of their choice. The one-hour long (roughly) interviews were conducted using an interview grid with closed-ended questions (e.g., age, number of years of experience, and number of HIV/AIDS patients) and open-ended questions (e.g., What were the "wow moments" during your practice?) about the physicians' lived journeys caring for HIV/AIDS patients during the pandemic. Besides being audio-taped, a researcher journal was maintained to capture the researcher's impressions and perceptions following each interview. The study used the period that included the start of the epidemic (around 1981) through to the said infection chronicity (around 1998), as well as up to the interview period, 2008-2009.

Six gay physicians, from large Canadian urban centres, responded to the invitation to participate in the study, thus forming the six cases. Their median age was 48 years old and their experience in the treatment of HIV/AIDS patients spanned an average of 19 years, with their medical practice consisting of 200 HIV/AIDS patients, in mean terms. The recruitment process of participants was purposive. They were recruited based on criteria[29,30] used by patients when choosing to consult a physician during the HIV/AIDS pandemic[2]. Patients sought out physicians who were involved and had experience in HIV/AIDS prevention and the treatment of HIV/AIDS patients. Moreover, they sought out physicians with the same sexual preference as theirs and who identified as being gay, as well as individuals who possessed a militancy background, i.e., mobilized and advocated for their patients and their community.

Data were collected using the complete audio-taped transcription of each interview assisted by "word processing software" (e.g., Atlas-ti). To allow for a preliminary analysis, the complete transcription of the audio tape for each interview was performed within 24 hours following the interview. Based on Merriam[31], as well as her peers[26–28], the data analysis steps included, in an iterative (successive and cumulative) manner, reading over the interview transcript (verbatim) and researcher journal after each interview session, to develop a certain familiarity with the data; create headings manually, and using the data processing software; and indicate recurrent ideas (e.g., notions, concepts, and themes). During the data analysis for each transcript, an iterative process was used to separate the data into the following categories: units of meaning, coding, categorization, and established relationships between them (e.g., commonalities, differences, and patterns)[2]. Following the last interview, an in-depth data analysis was conducted for each transcript and between transcripts. A peer-reviewed process of every interview transcript and presentations of the data's interpretation was done by the research team in order to establish the study's rigour and trustworthiness[31]. Finally, the study participants were asked to review the draft data interpretation of their interview for their comments and suggestions. Two physicians presented their comments and suggestions.

B) 2019 PAPER

Since the completion of the study in 2012, the ongoing literature review revealed new aspects of the topic at hand and produced different results at different moments. At the time of the study, a CD-ROM search was performed for the literature review. In addition to the CD-ROM results, the following sites were consulted for the paper: Google Scholar, Medline, ResearchGate, as well as the Virtual University of Ottawa Library, and the Internet to supplement the previous results.

Using the same list of words and themes identified in the study, the search found three studies related to the topic: Sherman and Ouellette[32]; Murbach[33]; and Lévy and Quévillion[34]. While these papers didn't address the topic from the same specific angle as the study, they offered addition information.

As examples, 1) Sherman and Ouellette talk about reasons for entering the AIDS care domain, rewards in caring for AIDS patients, aspects of the physician-patient therapeutic relationship, patient characteristics that promote a willingness and commitment to care, and the development of long-term reciprocal relationships with patients and partnerships in care[32]. 2) Murbach's study looks at experiences not previously accounted for in other studies, such as physicians and other medical personnel's obligation to attempt to care for, and treat HIV/AIDS patients, cultural differences and alternative medicine, and honesty in the context of research trials. 3) Lévy and Quévillon present a paper that speaks about the "emotional" sphere experienced by physicians in terms of its connection to the HIV disease, which could be expressed by ambivalent feelings. While these feelings were comparable to those mentioned by patients, such as rage, revolt, and hope, they also included compassion, fear, and culpability.

Through the same literature review, two books from physicians who became HIV/AIDS patients surfaced, one by Doctor Johnson, titled *Working on a Miracle*[35], and another by Doctor Waddell, called *Gay Olympian: The Life and Death of Dr. Tom Waddell*[36]. However, the emphasis of both books was not in line with the topic of the research, i.e., they talked about their struggle with the HIV virus.

C) 2024 ADDENDUM

Following the same pattern used for the study and the paper, a literature review was conducted using the list of words and themes identified above. In addition to the database from the 2019 paper, other sites were included. Ultimately, information was gathered from the following databases: Academia.edu, Academia Search Complete, APA PsycINFO, Canadian Major Dailies, CINAHL, Education Sources, EMBRACE, Érudit, EUREKA, FACTIVA, Google Scholar, JSTOR, Medline, Nursing Allied Health Premium, PODT, ProQuest, PubMed, ResearchGate, SCOPUS, Web of Science, as well as the Virtual University of Ottawa Library, and the Internet. The results from that search are presented below in the literature review.

Literature Review

At the time of the preparation of the addendum, several books from different types of authors surfaced. The first type consisted of six books written by gay doctors about their lived journeys caring for HIV/AIDS patients during the pandemic, namely, *AIDS: A Matter of Urgency: A Doctor's Memoir*[37], by Doctor Valenti; *One Life at a Time: An American Doctor's Memoir of AIDS in Botswana*[38], by Doctor Baxter; *Tell me I'm Okay: A Doctor's Story*[39], by Doctor Bradford; *My Epidemic: An AIDS Memoir of One Man's Struggle as Doctor, Patient, and Survivor*[40], by Doctor Faulk; and *Plague Years: A Doctor's Journey through the AIDS Crisis*[41], by Doctor Slotten. Their narratives, in some instances, parallel the results found in the study (e.g., the new therapeutic physician-patient relationship), and in other instances, they add valuable information on the topic, as shown in the results section of this paper.

The second type of material, found during the same literature review, comprised of books mostly from other gay and heterosexual healthcare providers (e.g., nurses and one female doctor) from the gay community. Such publications included, but were not limited to: Nurse Ferri's, (presently an HIV/AIDS Doctor) book titled *Wounded Healer: Confessions of a Male Nurse*[42], Nurse Munro's book titled *The Lived Experience of Gay Men Caring for Others with HIV/AIDS*[43], Doctor Ball's book titled *Voices in the Band: A Doctor, her Patients, and how the Outlook on AIDS Care Changed from Doomed to Hopeful*[44], Nurse Czerwiec's book titled *Taking Turns: Stories from HIV/AIDS Care Unit 371*[45], Nurse Varsalone's book titled *My Journey as an AIDS Nurses*[46], Nurses Matzer and Hugues' book titled *Nurses on the Inside: Stories of the HIV/AIDS Epidemic in NYC*[47], Doctor Fournier's book titled *The Zombie Curse: A Doctor's 25-Year Journey into the Heart of the AIDS Epidemic in Haiti*[48], Kidder's book titled *Mountains Beyond Mountains: The Quest of Dr. Paul Farmer: A Man Who Would Cure the World*[49], Pogash's book titled *As Real As It Gets: The Life of a Hospital at the Center of the AIDS Epidemic*[50], Shalof's book tilted *A Nurse's Story: Life, Death and in-between in an Intensive Care Unit*[51], and Dr. Vanderpuye-Donton's book titled *Hardship and Hope: Dr. Naa's Love Affair with Persons Living with HIV and AIDS*[52]. These books contained valuable information pertaining to their lived journeys during the HIV/AIDS and in some instances parallel the results found in the study and the paper (e.g., modifications to the therapeutic relationship). This new information will be presented in a research paper that we are planning to publish later.

Results

In the introduction, we mentioned that unused material (dilemmas/information) from the study was not included in the 2019 paper because of various constraints, such as paper length restrictions. The first part of the results section reiterates dilemmas/information previously published in the 2019 paper, while the second part contains dilemmas/ information not previously published in the 2019 paper. The third part brings foreword new material (dilemmas/information) from a 2024 literature review. They are mainly presented under two categories, namely: the transformation of the physicians' personal and professional identities; and the transformation of the physician-patient relationship.

1) PREVIOUSLY PUBLISHED MATERIAL FROM THE 2012 STUDY IN THE 2019 PAPER

The paper mentions numerous dilemmas mentioned in the study under the transformation of the physicians' personal and professional identities category, such as dilemmas about their perception of death, time, risk, euthanasia, aggressive and futile therapies, and the Faculty of Medicine and the College of Physicians, as well as about the traditional places to practice medicine, their physical and professional limitations, scientific and medical (un)certainties, and medicine in general. Under the physician-patient relationships category, the paper cites the following information. Physicians were compelled to adopt a more egalitarian therapeutic approach and engage in sustained and challenging therapeutic conversations with patients. Therefore, they had to stop to actively confront, judge, or even ignore their patients; start to explain the decisions they made regrading their patients' health; and begin to pay more attention to their choice of words. Physicians realized that they had to strengthen the criteria surrounding privacy; they had a "history" with their patients before they were diagnosed, up to their death, and beyond; that a role reversal could take place (patients taking care of physicians); and that the therapeutic border in the physician-patient relationship was blurring and that it needed to be rebuilt. Finally, physicians developed a greater understanding of their patients' distress, helplessness, and rejection. Under the professional, pharmaceutical, and community network relationships category, physicians were obliged to transform the way they viewed and dealt with other key networks. They had to develop and nurture new contacts who were sympathetic to their cause, such as pharmacists, medical specialists, pharmaceutical companies, and gay organizations.

2) UNPUBLISHED MATERIAL FROM THE 2012 STUDY IN THE 2019 PAPER

In the transformation of physicians' personal and professional identities category, the study mentioned that physicians had to reassess their therapeutic framework, and to re-evaluate their perceived inability to do anything to reduce the infection's occurrence or mitigate its psychological and physical effects on their patients. This unspoken 'ambiguity' questions their ability to treat, care and attempt to cure/heal their HIV/AIDS patients. As the pandemic was a new reality for them, they felt that they were practicing medicine in a state of 'ignorance', not knowing the origin of the disease and its transmission, as well as how to treat various infections HIV/AIDS patients developed. While being deep inside unknown territory, they experienced existential situations/ dilemmas that question life itself; their professional exclusivity and the patients' fidelity; the inability of some patients (and families) to cope with death; their cognitive limitations; the use of information technology; and the physicians' relationship to the disease.

A dilemma about life. As they rubbed shoulders with death every day, physicians had to change the way they approached life. "Live life fully"[2] and "One day at a time"[2] are two expressions prevalent in our popular culture that illustrate how they felt.

A dilemma about the professional exclusivity and fidelity of their patients. Physicians noticed that they had to be as 'accurate' as possible when giving information and diagnoses to their patients, since "their patients had two or more specialists"[2], some "visiting as many as five or six"[2], to treat their HIV/AIDS condition. This amalgamation of information from various specialists could easily create confusion for the patient and the physician.

A dilemma about patients' inability to cope with death. Physicians realized that some patients "were unable to cope with death"[2], and that "the family and the patient had not (never) faced death before"[2].

A dilemma about their cognitive limitations. As HIV and AIDS were new medical conditions, physicians did not have enough information to deal with them. Therefore, they often found themselves in the untenable situation of having to tell their patients that they did not know "what they had"[2] or "how they caught it"[2], and that their medical expertise had reached its limit when it came to the treatment to prescribe.

A dilemma about information technology. As technology became more prevalent in society with the use of Internet and cell phones, physicians needed to harness the power of emerging technologies and use them to stay up to date about illnesses, drug interactions, treatments (conventional, alternative, and unconventional), drugs (conventional, unconventional, or experimental), and remain in contact with the gay community. They also had to educate patients about reliable sources of information versus the plethora of false information they could have come across[2].

A dilemma about their relationship with the disease. Physicians learned that they did not "have to be HIV positive to treat patients with the disease"[2]. On the contrary, they "had to remain as healthy as possible"[2] to effectively care for their HIV/AIDS patients.

Following the growth of the HIV/AIDS pandemic, physicians talked about perspective transformations in the physician-patient therapeutic relationship. Physicians were aware of the 'power' they gained "through what my (their) patients tell me (them) so that I (they) may advise them and try to intervene where I (they) believe it is (was) possible and appropriate"[2]. Such conversations included information about their patient's "intimate lives." Therefore, physicians were at the same time doctors and sex educators[2].

A dilemma about the paternalistic medical model. Finally, some physicians dissociated themselves from the profession's paternalistic medical model they learned during their studies[53]. The top-down relationship (physician- centred) became a patient-centred relationship. They took a stance by being open about their own sexual orientation, which played a role in shaping the way they ultimately interacted with patients and practiced medicine.

3) NEW INFORMATION SINCE THE PUBLICATION OF THE 2019 PAPER

Since the publication of the paper, my colleague and I continued our search for new literature pertaining to HIV and AIDS, and more specifically, concerning the lived journeys of gay physicians caring for HIV/AIDS patients during the pandemic. During the pandemic, physicians did not publicly reveal that they were gay (or not) probably because they were afraid of discrimination and even ostracization. Since the first data collection for the study, many physicians retired from the medical profession, and are now able to come 'out of the closet' and tell their uncensored story as openly gay physicians caring for HIV/AIDS patients during the pandemic. We could speculate that they are no longer afraid of reprisal from patients, colleagues and/or even professional governing bodies, such as the College of Medicine. Whatever their reasoning, they finally decided to disclose their lived journeys by writing down their own experiences/journeys while caring for HIV/AIDS patients during the pandemic. The following are the lived journeys and dilemmas of five gay physicians: Doctors Valenti, Baxter, Bradford, Faulk, and Slotten. They are presented here in chronological order.

Doctor Valenti's book titled *AIDS: A Matter of Urgency: A Doctor's Memoir*[37], published in 2017, adds significantly to the discourse about the complex myriad of dilemmas physicians faced during the HIV/AIDS pandemic. But first, he emphasizes that "the clinical care of HIV(/AIDS) patients during the pandemic was, and has been provided by gay men, women, and minorities in large part"[37], and that their lives "became part of our (their) work"[37]. Moreso, "my (their) friends became my (their) patients and my (their) patients became my (their) friends"[37].

When talking about dilemmas, he notes that "the (HIV/)AIDS epidemic (pandemic) would be a test of our (their) spirituality"[37], values and beliefs. He also mentions that many new words appeared in the medical arena that they tried to understand both the meaning of and how they interlock. The following are examples of those words:

"Body fluids, health crisis, incurable illness, the epidemic, pandemic, AIDS crisis, death sentence, AIDS hysteria, the virus, lymphadenopathy-associated virus (LAV), high-risk groups, safe sex, safer sex, injection drug use, haemophiliacs, Haitians, AIDS babies, children with AIDS, women with AIDS, transfusions, occupational exposure, antibody test, gay-related immune deficiency (GRID), AIDS-related complex (ARC), gay plague, AIDS victims, pneumocystis pneumonia, inhaled pentamidine, dextran sulfate (sulphate), AL-721, Compound Q, Kaposi's sarcoma, cryptosporidiosis, molluscum contagiosum, hairy leukoplakia, thrush, lymphadenopathy syndrome, AIDS wasting, and the ACT UP advocates' signature: "Silence=Death"[37], as such "information came in fragments"[37(in italics in the original text)].

"Like battle-weary frontline veterans, Valenti continues his narrative by talking about situations that happened during their long days at work and dilemmas they experienced.

The medical war (against HIV/AIDS) required us (them) to think ahead, advocate for patients, and be aggressive. We (they) never knew what decisions would need to be made when we (they) went to the office each day. In fact, we (they) learned to expect the unexpected, waiting for the other shoe to fall. We (they) found ourselves (themselves) in a thick fog of issues none of us (them) had ever encountered, quick decisions to be made, patients sick and in crisis, and death everywhere"[37].

"He mentions the critical dilemma physician faced as they were performing "(some) things that had never been done before"[37]; something they had never encountered at the Faculty of Medicine. In fact, they were the vanguard of the medical response to the pandemic, expected to handle the tsunami of developing issues without complaint, frequently blazing new trails by "working at the "top of your (their) license"[37]. This dilemma could be characterized by the expression, "flying by the seats of our (their) pants"[37].

Valenti also indicates that physicians faced a dilemma when "voluntary"[37] or "mandatory"[37] HIV testing became a major issue. Moreover, he notes the dilemma surrounding some of the places physicians had to practice medicine, such as an "underground clinic"[37]. Finally, he mentions the daunting dilemma of treating "innocent victims"[37] of HIV, such as "children and people with haemophilia, versus gay men and injection drug users"[37].

In the paper, we presented a book from Doctor Baxter titled *The Least of these my Brethren: A Doctor's Story of Hope and Miracles on an Inner-City AIDS Ward*[17], published in 1997. In that book, Baxter did not mention that he was a gay doctor. In 2018, Doctor Baxter published a second book called: *One Life at a Time: An American Doctor's Memoir of AIDS in Botswana*[38]. After the publication of his second book, Baxter revealed his sexual orientation during an interview with William Giraldi from the Los Angeles Review of Books (LARB)[54] where he acknowledged that he was "a sexually active gay man"[54]. While these two books are set in very different environments and periods of the pandemic, they both substantiate the many dilemmas stated in the study and the paper, such as the risks physician encountered while treating their HIV/AIDS patients, and the numerous times they crossed the physician-patient boundary.

In his second book, Baxter contributes to the list of dilemmas by writing about the physicians' obligation to treat patients regardless of their diseases. In fact, "many hospitals and medical clinics (as well as health care workers) refused to care for them, or else treated them like untouchables (leapers), relegated to distant isolation wards"[38]. The author also mentions at multiple occasions that physicians faced situations when patients rebounded from their infection(s), "even sending them home after they recovered"[38]. Unfortunately, they came back to the hospital until the antiretroviral treatments appeared, where patients rebounded and even went on to lead productive lives. As Baxter notes, "patients were literally getting out of their deathbeds, returning to their former selves. Even minds ravaged by HIV dementia were gradually restored"[38]. Finally, Baxter also mentions the dilemma that physicians faced when encountering denialists, governments, or individuals, who challenged them. For example,

"Over whether HIV was a problem he (conference attendee) needed to worry about: "Look at me: I've had sex with hundreds of women, and I feel totally fine! This HIV is not true! Not true!" People around him nodded their support, some of them laughing at our cluelessness"[38].

In Doctor Bradford's book titled *Tell me I'm Okay: A Doctor's Story*[39], published in 2018, he concurs with many of the dilemmas cited before, such as crossing the physician-patient boundary[39]. That example was very explicit when a patient told him he had "added my (his) name and home phone number to the piece of paper and handed it to him, saying, […] You can contact me any time, day or night"[39]. He also talks about the ethical dilemma of testing patients "without the patient's knowledge"[39]. In addition, he notes the dilemma of the "long-term non-progressors because their immune systems controlled the virus longer than the average patient"[39].

In his book titled *My Epidemic: An AIDS Memoir of One Man's Struggle as Doctor,* *Patient, and Survivor*[40], published in 2020, Doctor Faulk presents his "very personal experience with AIDS in which I (he) found myself (himself) as a (gay) doctor, patient, and survivor"[40].

Similarly to many of his peers, he often crossed boundaries, such as having "no reticence about (having patients) calling me (him) no matter the hour"[40]. He also talks about denial, and in this case, his own denial[40]. As for many physicians, he mentions that "it was time for me (him) to stop living in the future and begin living in the present"[40]. This author continues his recollection of the events by mentioning his physical limits, "not being indestructible"[40], and being "human"[40], and not being able to "please everyone"[40]. As with the preceding physician, he heard that some physicians were "refusing to care for HIV patients"[40]. In addition to dilemmas recounted by other physicians, this author brought situations that were not mentioned before, such as "frequent lab hiccup(s)"[40] where physicians received false positive or negative results to share with patients, and where another test had to be performed, adding to the stress of the patient. As patient-physician boundaries were often blurry, Faulk was careful when encountering patients on the street. During these encounters, he said: "I never acknowledge a patient first. Without their greeting, I behave as if I'd never seen them"[40]. Finally, Faulk talks about HIV/AIDS physicians' dilemma regarding "self-treatment"[40]. Faulk talked about the dilemma regarding "long-term survivors"[40] and those who seem immune to the HIV virus because of a CCR5 gene[40]. Finally, he also talks about the dilemma pertaining to patients who rebound, "slowly begin to improve"[40], and survive, and the "survivor guilt felt by them"[40], the "Lazarus Syndrome"[40].

Finally, Doctor Slotten published, in 2020, a book titled *Plague Years: A Doctor's Journey through the AIDS Crisis*[41]. Like other physicians from the study, he quickly realized his limitations and often crossed the physician-patient boundary[41]. He mentions,

"I wasn't healing anyone. I was ministering to my patients, as doctors did in the pre-antibiotic era, doling out bad news, holding a hand in sympathy, or expressing my condolences in the face of an incurable, fatal disease. I felt more like a failure than a success, even though HIV-infected gay men from far and wide sought me out because of my expertise and reputation"[41].

He also talks about the dilemma pertaining to patients who rebounded[41]. This author mentions his physical limitations and the "specter (spectre) of his mortality,"[41(p71)] and the dilemma of denial[41]. According to his experience, some physicians were "interested only in accruing subjects for a clinical trial to enhance his (their) reputation, puff his (their) curriculum vitae for future government pharmaceutical grants, or supplement his (their) income, but indifferent to the patients in the study"[41]. Finally, there is the dilemma of long-term survivors. As Slotten puts it,

"They're the walking wounded, their impairment no less real or legitimate than that of the traumatized soldier who witnessed the deaths of comrades or escaped his own death by the skin of his teeth"[41].

Discussion

To contextualise the relationship between the three documents, this section will first, review some concerns, comments, and suggestions from the study and the paper. Second, it will address the concerns, comments, and suggestions from the addendum.

The study: Its content presents dilemmas that emerged from six interviews and the analysis of previously published autobiographies from non-'gay' authors. As there were only six cases (gay physicians), it would have been audacious to conclude that the results were complete with respect to the dilemmas physicians faced while caring for HIV/AIDS patients during pandemic. There is no doubt that other dilemmas could be added to the list. Nevertheless, the study mentions dilemmas that explain the transformation of their personal and professional identities, and their relationships to their patients and networks[2].

The paper: Its narrative brings together three types of findings, several dilemmas mentioned in the study and in the literature review, as well other caregivers from the gay community. These findings additionally highlight the extent to which physicians had to transform and learn to care for HIV/AIDS patients. However, a lack of gay specific literature still causes concerns as to the veracity and the depth of the data gather through the interviews.

The addendum: It chronicles an overview of the study and paper results, but more so, brings to the forefront, unused material not previously published. The content of this unused material was later confirmed as relevant today by a new literature review. These new findings bring an additional breadth and depth to the previous findings. First, they confirm the initial findings, second, they add context and content to those findings, and third, they bring to light dilemmas encountered by gay physicians caring for HIV/AIDS patients during the pandemic not previously mentioned.

The unused material presented in the addendum brought additional information regarding two metamorphic categories: 1) the transformation of the physicians' personal and professional identities; 2) the transformation of the physician-patient relationship. Both categories speak volumes to the changes that happened to physicians during the pandemic. Physicians needed to adapt quickly. The pandemic revealed situations/dilemmas that they never learned during their studies and training. As examples, dilemmas about life and death, and about patients not able to cope with death. These dilemmas were new realities during a very difficult time. The treatment of HIV/AIDS patients required an approach that was less paternalistic and more patient centric. In other words, physicians were not discriminating and stigmatizing their patients when, as an example, it came time to discuss their lifestyle. Finally, physicians had to build networks of professionals who were sympathetic to their causes/battles and develop links with social movements to increase the support networks for their patients.

The recapitalisation of situations/dilemmas from the study serves two purposes: first, to showcase the relevancy of these situations/dilemmas today by (second) substantiating it with a new literature review. In fact, the results from the more recent literature review confirm the importance of the physician–patient therapeutic relationship without discrimination and stigmatisation. Central to the physician-patient relationship is the patient's needs. If discrimination and stigmatisation persist, the patient's needs won't be recognized by health and social services, as examples, won't be addressed and improved. Discrimination and stigmatisation can also affect the physician. It is possible that physicians who would have revealed their sexual orientation would have been ostracized by their peers and the College of Medicine. The situation Baxter, mentioned above, is a good example of a physician in such a situation. He revealed his sexual orientation possibly after retirement and the publication of his second book. As a gay physician, he was aware of how HIV/AIDS patients were treated during the pandemic. For him, medical establishments (hospitals and clinics) and health care workers (physicians and nurses) have an obligation to treat patients regardless of their diseases.[38] For a gay physician, the boundary between physician-patient becomes a tangible reality when the gay physician could eventually be a patient.

Research Implications

It is important to emphasize that the study, the paper, and the addendum revealed research implications that are equivalently associated with the patients' needs, the medical practice, and various stakeholders. As mentioned in the 2019 paper, a closer look at these research implications shows that the treatment of patients, especially in time of crisis, challenges the traditional evidence-based medicine and provokes new practices. Moreover, they produced new scientific knowledge that increases the professional–patient relationship and the value of the patient who becomes more involved in the process of healing (patient informant and patient empowerment) through research trials.

During the recent literature review, we found that other healthcare providers from the gay community have published valuable information pertaining to their lived journeys while caring for HIV/AIDS patients during the pandemic. The publications that surfaced brought to light the work of gay nurses' lived journeys during the HIV/AIDS pandemic. They are, in chronological order: Nurse Richard S. Ferri's, (presently an HIV/AIDS Doctor) book titled *Wounded Healer: Confessions of a Male Nurse*[42], published in 2005; Nurse Ian Munro's book titled *The Lived Experience of Gay Men Caring for Others with HIV/AIDS*[43], published in 2008; Doctor Susan C. Ball's book titled *Voices in the Band: A Doctor, her Patients, and how the Outlook on AIDS Care Changed from Doomed to Hopeful*[44], published in 2015; Nurse (MK) MaryKay Czerwiec's medicine graphic book titled *Taking Turns: Stories from HIV/AIDS care unit 371*[45], published in 2017; Nurse Dominick P. Varsalone's book titled *My Journey as an AIDS* Nurses[46], published in 2016; and Nurses Ellen Matzer and Valery Hugues' book titled *Nurses on the Inside: Stories of the HIV/AIDS Epidemic in NYC*[47], published in 2019. As well, three papers were found with nurses caring for HIV/AIDS patients as topic of interest. In 1992, Bennett wrote *The Experience of Nurses Working with Hospitalized AIDS Patients*[55]; in 1994, McGarrahan published a research study titled *Transcending AIDS: Nurses and HIV Patients in New York City*[56]; and in 2000, Sherman prepared the paper titled AIDS-Dedicated Nurses: What Can Be Learned from their Perceptions and Experiences[57]).

Because of the interest created by the study and the paper, we decided to move our research interest from gay physicians to gay nurses. This new paper's interest lies in the fact that nurses have an increased proximity with patients; therefore, they may have had similar or different lived experiences with HIV/AIDS patients during the pandemic than their gay physician counterparts. As Matzer and Hugues put it,

"There were hundreds of nurses who went through this experience. They (and others) want to tell this story to give a voice to a generation lost, encouraging the world to remember one simple thing; this history cannot be repeated"[47].

Conclusion

The intent of this addendum was three-fold. First, it aimed to recall information from previous documents (study and paper), and second, add unused material in the results section of the paper titled *Unsung Heroes: Gay Physicians' Lived Journeys During the HIV/AIDS Pandemic*[1] using as basis the data from the PhD Thesis (study) titled *Recours à l'apprentissage expérientiel dans la transformation de la pratique médicale de six professionnels pendant la pandémie du VIH/sida*[2]. Third, it intended to update the literature review with recently uncovered publications pertaining to gay physicians' lived journeys while caring for HIV/AIDS patients during the pandemic.

The results section of the paper was strengthened with unused material that dealt with the transformation of the physicians' personal and professional identities (e.g., different medical framework) and the transformation of the physician-patient relationship (e.g., less paternalistic, more patient centric, and crossing the fine boundary between physicians and patients).

The new literature brought to light a novel cohort of books published by gay physicians who cared for HIV/AIDS patients during the pandemic. For reasons, such as the absence of reprisal, discrimination, or ostracization, as they had retired from the profession, they took the time to write about their priceless lived experiences while caring for HIV/AIDS patients during the pandemic.

These books added valuable information about the lived journeys of gay physicians during the pandemic and the situations/dilemmas they encountered while caring for HIV/AIDS patients during that period. What is noteworthy is that physicians were constantly at the heart of the debate on how to treat HIV/AIDS patients, especially when they encountered, as examples, denialists, governments, or individuals who challenged them about their work.

The study, the paper, and this addendum led us to the discovery of a new cohort of books, this time about gay nurses' lived journeys during the HIV/AIDS pandemic. Consequently, we are moving our research interest from gay physicians to gay nurses to discover if they had similar or different lived experiences than their gay physician counterparts, in the same context. As nurses had an impact on their HIV/AIDS patients' lives, this next paper will aim to give them a space where they can recall their lived journeys while caring for HIV/AIDS patients during the pandemic.

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Appendix 1 HIV-AIDS Pandemic Trajectory: Three Periods

Period 1—HIV/AIDS Emergence

Patients: Gay individuals who contracted the HIV infection

- Isolated and destitute
- Little or badly informed

Medical Practitioners: Generalists

- Little solidarity with patients
- Generally little militancy activities
- Interested by knowledge, but little engagement in new required knowledge production

Gay Social Movements: Against HIV

- Non-existent or non-visible

Period 2—Recognized Pandemic and Militancy Rise

Patients: Gay individuals who contracted the HIV infection

- Militancy rise
- Active search for information
- Participation in conferences, seminars, and workshops

Medical Practitioners: Gay generalists

- New medical practice mode (experimental medicine, experiential learning used)
- Committed to knowledge production, not only its use
- Institutionalized knowledge and traditional continuing medical education modes challenged
- Patient solidarity, militancy

Gay Social Movements: Against HIV

- Visions and alternative medical knowledge production
- Provides members with a range of services and training

Period 3—HIV Chronicity and Militancy Decrease

Patients: Gay individuals who contracted the HIV infection

- Militancy and empowerment decline
- Conferences, seminars, and workshop participation decline

Medical Practitioners: Gay generalists

- Initial and continuing medical education integrate new knowledge (knowledge institutionalization)
- Medical practice centered mainly on the preservation of health and the cure of diseases
- Experimental medicine continues, but less engaged in knowledge production
- HIV infection increasingly considered chronic (an "implicit expectation" that infected individuals will survive the HIV infection)

Gay Social Movements: Against HIV

- Fewer militancy organizations
- Have difficulty recruiting volunteers
- Focused on specialized service provision