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**Misinformation During Health Crises: Will We Ever Learn?**

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Literature Review Project Dissertation

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# Abstract

Misinformation during times of serious health emergencies can be equally as dangerous as the disease itself. Blind belief in information from governmental bodies, classical forms of media, and now social media has proven to be costly and sometimes fatal. This paper discusses numerous sources of dangerous information that so often creates stigmas and prejudices and explain the consequences of such, finally proposing methods to avoid this in the future. Fear and panic created by misinformed or ill-worded government campaigns and through scaremongering by media outlets posed a substantial challenge to developing our understanding of and preventing deaths in, early pandemics, such as the HIV pandemic in the 80s and 90s, as well as the early period of the anti-MMR movement – a time associated with slow information transfer before the advent of the internet. In a world intertwined with social media, these problems have only been exacerbated and the need for solutions to prevent the spread of harmful information is more urgent than ever during the current COVID-19 pandemic.

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# Abbreviations

**Measles, Mumps, and Rubella (MMR)**

**People with AIDS (PWA)**

**Anti-vaccination (anti-vax)**

**Antiretrovirals (ARVs)**

**Highly active antiretroviral therapy (HAART)**

# Introduction

In the age of social media, misinformation can spread equally as fast as a disease in times of pandemonium and often prove deadly to people who fall victim to following its advice (1-4). 800 people in Iran died and another 60 were left permanently blind after drinking concentrated ethanol, a treatment falsely reported to kill the virus (1). The spread of negative stigmas and incorrect information cannot be thought of as just a modern occurrence; ignorance surrounding HIV in the 1980s and 90s, as well as refusal of the Measles, Mumps, and Rubella (MMR) vaccine leading up to the turn of the century, can attest to this. While first developing more than 40 and 20 years ago respectively, the effects of falsified and incorrect information, news, and propagation of negative stigmas have had a lasting effect on public opinion (5,6). In the modern world, social media has provided a platform for conspiracy theorists and pseudo-scientists to peddle incorrect information as scientific fact, creating a breeding ground for the resurgence of outdated views and beliefs (1). At no time in recent history has this been more prevalent than during the COVID-19 pandemic (7,8). In this work, the potential damage of misinformation will be detailed while highlighting that the crucial component to preventing future cases is science communication. Responsibility does not fall on scientists to prevent infodemics – the rapid spreading of information, correct and incorrect, often referring to disease – but rather on those that communicate their work to the public: politicians, officials, economists, journalists, celebrities, and even the man in the street.

# HIV/AIDS a 40 Year-Long Pandemic.

While HIV is believed to have existed from at least the 1920s, it was thrust into global notoriety in the early 1980s when gay men in New York and California began to show an impairment of their immune response leading to deaths from several rare diseases – later being attributed to AIDS (9). HIV is a lentivirus that attacks the immune system, specifically gaining entrance to helper T lymphocytes by facilitating virus-cell fusion via the gp41 envelope protein that decorates HIV-1 viruses (10). The early stages of a now 40-year pandemic played out not on social media but through newspapers, tabloids, articles, and government-backed TV campaigns. The spread of misinformation was slower but showed it was still capable of creating stigmas and prejudice. The stigma that people with AIDS (PWA) face can be well epitomised by the Centres for Disease Control and Prevention (CDC)’s choice to initially name the disease GRID – Gay-Related Immune Deficiency (11). A poll in the *Los Angeles Times* found that on average throughout 1985-88, over 25% of respondents believed that HIV was an act of God, punishing homosexuals for the way they lived (12). Even when now-infamous campaigns aimed to prevent death through ignorance (figure 1), highlighting anyone can contract HIV, this created societal fear among those least likely to get HIV and fed prejudice towards those suffering from HIV. The way HIV was first communicated to the public greatly impacted the quality-of-life PWA had and shows the importance of conveying accurate science, and the role that media plays in health crises.

HIV in this first generation will be remembered for its large loss of life and the misinformation that caused it. A particularly notable period was under President Mbeki of South Africa which saw the preventable deaths of over 300,000 people. In the early 2000s, at the height of many countries' HIV peaks, South Africa was “slow to embrace treatment rationale”, according to Stephen Lewis – UN Special Envoy for AIDS in Africa at the time (13). The inaction and subsequent deaths of many South Africans stemmed from misinformation: natural treatments and the demonising of antiretroviral drugs (ARVs) by the health minister, Tshabalala-Msimang, largely contributed to it (14). ARVs were and still are the most effective treatment options for HIV. These drugs aim to target the reverse transcriptase used by HIV-1, proteins such as gp41 that facilitate fusion with cell membranes, and the protease used to cleave the polyprotein produced from its RNA genome. Highly active antiretroviral therapy (HAART), the combined use of three drugs to target all aspects of HIV-1, was available in the 2000s and greatly reduced fatality rates. By targeting three key features of HIV, it prevented drug resistance and reduced viral load to levels undetectable by sensitive assays, <50 RNA copies per ml (15).

The early period of HIV/AIDS was not one of complete negativity. Princess Diana’s work for PWA was important for challenging stigma, creating a direct challenge to the circulating misinformation, and helping positively impact public opinion at the time (16). Charities were also established to help PWA; one of the most important in the UK was and remains The Terrence Higgins Trust. They aimed to bring the growing epidemic to the attention of the British government, raise awareness among the general population for those suffering from AIDS, spread accurate information, and fund research (11). While it can be said celebrities and charities should not be expected to correct misinformation, their platforms give them a voice that too often scientists are not given. The para-social relationships people cultivate with celebrities gives them a great deal of influence; a unique quality that can be used to positively impact public health.



**(figure 1: ad campaigns that ran in the UK and Australia, highlighting the lethality of HIV using a tombstone and the grim reaper respectively. [see reference list])**

# MMR and the Rise of the Anti-Vax Movement

One of the single most controversial instances of misinformation becoming mainstream belief stems from a 1998 publication by Andrew Wakefield linking the measles/mumps/rubella (MMR) vaccine to autism in children; a piece accused of being “a deliberate fraud” by the *British Medical Journal* (17). While this cannot be deemed the birth of the anti-vaccination (anti-vax) movement, it marked a turning point in its evolution that brought it to the masses and ensured its propagation, allowing it to persist to this day (5,18). The role that traditional media played during the beginning of the anti-MMR movement cannot be understated, a parallel that can be drawn to the HIV pandemic. Scaremongering was used to peddle disingenuous beliefs in the name of selling papers, reducing the impact of scientific advice (19,20). The Daily Mail was renowned for its opposition to the MMR vaccine (figure 2)(21) and a systematic review by Catalan-Matamoros and Peñafiel-Saiz of articles published between 2007-17 found 75% contained negative stances towards vaccines and 83% lacked accurate information (22). The combination of unscrupulous publications from Wakefield and catchy, fear-inducing titles common in tabloids led to a drop in vaccine uptake to as low as 61% in areas of London (23) and a total drop from 92% in 1996 to 84% in 2003 (24). Any decrease in the vaccination rate can have deadly consequences for a population; greater scrutiny of publishable work by regulatory bodies and progress in the field of science communication to provide easier access to reliable information could have prevented the strongest resurgence in anti-vaccination beliefs ever seen.

The entrenched nature of the anti-vax movement can be seen as the world progressed online. The internet facilitates the spread of information faster than anything seen before it. While this has obvious positives, the negative ramifications of the unregulated spreading of information, regardless of provenance and accuracy, must be considered. As previously mentioned, social media has provided a platform for the masses and an ability to spread information that was once only available to medical professionals (25). While this has positives: collective ownership of intelligence and a democratising of the creation and transfer of knowledge, the insurmountable drawbacks of the dangerous spread of misinformation and the creation of stigmas and instances of hate speech and physical attacks cannot be overlooked. Here, I believe it is the failing of social media companies and their ability, or lack thereof, to regulate the information posted and shared on their platforms that has led to decreasing rates of vaccine uptake and potentially fatal and nonsensical scepticism. Both the UK and the US have seen recent outbreaks of measles and an overall drop in MMR vaccine uptake, long after the initial declines seen in the early 2000s (25,26). Developing a platform for scientists to convey their work to the public and having it written in such a way to make it more accessible would be a great help in spreading accurate information that is harder to misinterpret or misconstrue. Tighter regulation on social media sites, which disproportionately spread misinformation (27), is likely to make a great difference too; some have implemented this system and now mark posts with a warning indicating the information in them are not verified.

The UK Department of Health and Social Care blamed a lack of information for falling rates of MMR vaccine uptake. A 2022 survey, conducted by Freuds, using 2000 English parents who had children between 0-5 years old detailed that 48% of UK parents didn’t know the severity measles was associated with, and only 38% knew it could be fatal (28). These failings could come from encroaching complacency among healthcare providers and governmental bodies that have stopped advertising the necessity of vaccinations, in partnership with rising concerns over the COVID vaccine that has crucially increased scepticism of the technology (29). It is easy enough to offer the solution of greater focus on falling statistics and ensure positive campaigns are renewed continually, however this overlooks key monetary and logistical challenges that often prevent important government action.

A newspaper with a person's face on it

Description automatically generated with medium confidence

**(figure 2: an anti-vax article for the Daily Mail from October 2005. [see reference list])**

# Current Infodemics; COVID-19

The sweeping COVID-19 pandemic has gripped the world and created societal instability. Incidences of racism and motivated attacks towards Asian populations increased (30), many countries’ economies were severely impacted, causing a drop in standards of living (31), and many studies pointed to the impacts restrictions such as lockdowns had on people’s mental health, particularly in children (32-34). Conspiracy theories, the birth of stigmas, and the spreading of misinformation are visible on a variety of social media platforms that span the globe (1,35). Collectively, this can damage the reputation of genuine scientific advice and knowledge. Politicians and public figures, by nature of their potential outreach, hold the ability to influence vast numbers of people and in some cases whole groups of society, inciting positive and negative effects (36-38). Both the power of individuals sharing information en masse, and stand-alone messages from people in positions of notoriety or political stature can be, and has been, influential in the spreading of misinformation, fake news, conspiracy theories, and stigmas during the coronavirus pandemic (35-38); an unfortunate consequence of which saw people following unverified and potentially dangerous information, in some cases causing hospitalisations and death (3,4,39-41).

An important area to discuss is COVID denialism and downplaying the severity of the disease. President Jair Bolsonaro of Brazil is a denialist, as were many of his allies; he later caught COVID as did Olavo de Carvalho, the right-wing mentor of Bolsonaro, who died from its complications (42). The initial lack of response to COVID-19 was uncharacteristic for Brazil, whose healthcare system has an impressive level of vaccine uptake (96% for TB, diphtheria, polio, and hepatitis) (43). Despite claims by Bolsonaro that he would not get vaccinated, efforts from Brazil’s healthcare system have provided vaccines for some 75% of their population at the time of writing, however, slow rates in summer 2021 – at least half the rate of the UK, USA, and France in June 2021 (44) – lead to an unnecessary spike in hospitalisations and deaths. At the country’s peak, it was responsible for around 33% of global COVID-related daily deaths (roughly 4000 per day) (43); a fact that put immense strain on the healthcare system, causing a further escalation in cases and following death rates. Both Bolsonaro and former US president Trump were quick to downplay the severity of COVID-19, favouring their economies over their citizens' lives (45), and went as far as to oppose members of government who focused on health (45), condemning regional restrictions, while also managing to find time to promote untested, unverified, and ludicrous methods of treatment, often resulting in harm and some rare cases death (39,46). For context, the USA has the highest total case and death numbers, while Brazil has the second-highest number of deaths with the third-highest case count; importantly, however, Brazil has a higher rate of death than the USA, at 3000/million population compared to 2900/million (accurate at the time of writing) (47). Both examples show the impact that politicians have on influencing people regarding their health. Any government official has to provide their citizens with accurate information to allow them to make the best-informed decisions. A greater focus on science is key to this and there should be greater channels of communication between scientists and politicians.

The second area of intense focus during the COVID-19 pandemic has been the role social media played, both good and bad. Ex-president Trump very often used Twitter as his diary, writing and putting into the world seemingly any idea he had, as mentioned, often leading to dangerous actions by people who trusted him. This highlights a key issue faced by social media companies – the disproportionate effect that people in a position of notoriety hold. Notorious podcaster Joe Rogan has made numerous claims with little to no referencing of reputable scientific papers supporting them, a point that has increased the spread of misinformation and possibly harmful practices (48,49). Among the claims was a common anti-vax belief that a high risk of developing myocarditis is associated with having the vaccine; what was fortunately mentioned by Rogan’s guest is that there is an even greater risk of developing myocarditis after contracting SARS-CoV2, (50). Potentially more dangerous than political figures and celebrities are medical professionals who share blatantly incorrect information. An infamous video from the pandemic shows an anti-vax doctor, Dr Annie Bukacek, stating the CDC has encouraged the use of COVID on death certificates to highlight the severity of the disease and use this to infringe on US citizens’ rights (51) – a common conspiracy theory believed by federal government-averse members of society.

# Advice for the Future

Evidently, through three isolated incidences: the HIV pandemic spanning some 40 years, the worsening of the anti-vaccination movement during the early 2000s, and the current global crisis of COVID-19, the spread of misinformation has been seen at every level, from government officials to public figures and celebrities, to normal people sharing opinions on social media. This has led people to unnecessary harm, with many losing their lives or having had their mental health severely affected. Communication is at the centre of this issue. The onus is not on scientists to correct people for misconstruing their research for their own needs, or the spreading of entirely falsified information. While some scientists do take on this role, the responsibility falls on those that communicate their research to the public, including the public themselves with social media providing a voice to everyone. Institutes such as the Wellcome Trust and charities like the Terrence Higgins Trust play a vital role in providing accurate scientific information to the masses, as well as providing an advisory role to government officials and bodies on key issues. Classical forms of media are trusted sources of information to their subscribers and have a responsibility to produce scientifically sound articles that cannot lead to the detriment of people’s welfare – too often in the past this has not been upheld, and now with anyone able to publish information online on blogs and websites, it becomes a greater challenge yet. Politicians giving opinions on matters they have no prior knowledge of can lead to people following unverified advice, an issue seen with ex-president Trump and treatments for COVID. There is no magic bullet for tackling the spread of misinformation during health crises. These examples are part of a wider issue that has seen science becoming less trusted and less relied upon for information. The development of science communication at several levels, particularly in school systems, is a key step to re-establishing faith and trust in scientists and the work they do.

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