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## Perceptions of stakeholders on drivers of stigma subjected to People Living with HIV/AIDS (PLWHA) in Alice town, Eastern Cape: Implications for human rights and social service professions

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### ABSTRACT

Despite global HIV/AIDS stigma going down significantly, South Africa continues to experience both internal and external stigma that is believed to derail people's rights to prevention and response. It is therefore important to establish the drivers of stigma and the human rights deficit they pose to the PLWHA and to social workers. The article, through informal community engagements, sought to tap the insights of selected stakeholders on the drivers of stigma in Alice town and its environs. The study comprised thirty-three participants, eight of whom were engaged in in-depth interviews while 25 of them were involved in four focus group discussions. Coding facilitated the selection and establishment of themes. Findings established that stigma was driven by ignorance pertaining to the AIDS aetiology and epidemiology; weaker campaign infrastructure in the rural areas; poverty of the people; denialism and myths. The article has used the philosophy of Ubuntu to suggest how to tackle HIV/AIDS stigma. The article recommends more research on drivers of stigma. Collaboration, as well as a synergy between different stakeholders in the HIV/AIDS arena, is recommended.

**KEY TERMS:** AIDS aetiology, epidemiology, human rights, myths, denialism, traditional healers, Ubuntu

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## INTRODUCTION

While the world, as well as individual countries, have made remarkable progress and achieved pivotal milestones in the war against HIV/AIDS, the disease continues to be the cause of most fatalities and morbidities in South Africa and manifests stigma and stigmatisation. For example, even though the country has made huge improvements in getting people to test for HIV in recent years and is now almost meeting the first of the WHO 90-90-90 targets, paradoxically, the epidemic continues to place a huge hurdle to its economy. This is because the country runs the most expensive anti-retroviral drugs on the globe. Today, it is a refuge for 7.2 million people living with HIV. However, it is difficult to successfully make significant inroads to defeat the epidemic unless stigma and stigmatisation are subdued. Stigma continues to stifle's people's right to attain a full health status.

## BACKGROUND

The state of stigma in South Africa as in other countries still ravaged by HIV/AIDS has been identified as one of the biggest hurdles besetting a successful fight against the disease (Mavhunga, 2017); and remains an important barrier to seeking care and assistance among the PLWHA (Nyasulu et al., 2021). This is despite the country meeting the WHO 90-90-90 targets. These targets elucidate that by the year 2020, 90% of people with HIV infection are aware of their status, 90% of those aware are accessing antiretroviral treatments, and 90% are virologically suppressed (UNAIDS, 2017). Primarily, stigma dissuades people from accepting the disease and how to live positively with it or adopt a positive lifestyle; as well as promotes denialism and fear as a coping mechanism. It stifles people's right to achieve a clean bill of health. Perhaps a striking downside of stigma is making people living with HIV/AIDS shun disclosing their status (Kang'ethe, 2020). Infact, stigma is both the cause and effect of secrecy and denial, which perpetuate HIV transmission (Mall et al., 2013). This affects the HIV/AIDS campaign in that living with the disease shuns people from coming out for help. Inopportunately, stigma prevents people from disclosing their status and therefore resulting in a reduced need for behavioural change (Alemu et al., 2013). Disclosure, therefore, is important as it forms a platform for encouraging those who are HIV-positive to cope with the disease. Opportunately, those who disclose are also able to encourage others to strengthen their coping (Mavhunga, 2017). It is still imperative that the government amid other AIDS-friendly stakeholders such as the NGOs position qualified and adequate members of the social service profession, such as social workers, to strengthen the anti-stigma campaign and lessons.

According to Kang'ethe (2020), and reinforcing the ideologies of the societal stigma associated with diseases by Irving Goffman, the father of the discourse of stigma, stigma constitutes an act of disapproval of, or discontent with a particular individual on the grounds of characteristics that distinguish them from other members of the community and poses a psycho-social challenge that deters one from freely mixing with people (Lucksted & Drapalski, 2015). This, therefore, compromises one's level of dignity, assertiveness, self-worth, freedom, confidence and integrity, and human rights (Trevithick, 2012). This means that the anti-stigma campaign needs to be strengthened especially by the social workers both in the government and NGOs.

Stigma is also exacerbated by people not knowing the aetiology and epidemiology of HIV/AIDS well, and the quality and nature of information people are fed. This places the role of advocacy and meaningful information dissemination machinery, which this researcher believes can be effectuated by members of social service professions, such as social workers. People have the right to education and advocacy that takes away their ignorance which makes them susceptible to HIV/AIDS and its concomitant consequences (Obermeyer et al., 2011)

Further, people's ignorance coupled with denialism is also a critical ingredient of stigma. With the level of ignorance subsiding in many countries due to concerted efforts of their governments' campaign machinery in tandem with the spirited efforts of the NGOs in the HIV/AIDS domain, the fear that clouds and shrouds the disease is also waning, though not at a significant satisfactory level (Kang'ethe, 2020). Another downside effect of the disease is denialism associated with living with HIV/AIDS. People, through anti-stigma campaigns and advocacy, have the right to be saved from stigma, so that they can take their medication with ease, consistently, and correctly (Obermeyer et al., 2011). It is critical then that the government and the NGOs train to capacitate the workforce with HIV/AIDS education such as the anti-stigma and anti-stigmatisation messages to help people strengthen their response to the disease. Social workers should be at the frontline of this message and training dissemination process.

## Problem statement

Despite people living with HIV/AIDS increasingly getting a new lease on life due to massive access to anti-retroviral drugs, stigma manifesting in denialism, and hatred, continues to derail the fight against HIV/AIDS in South Africa and is believed to exacerbate the increase in infections. This is dire because 7.2 million people are statistically believed to be living with HIV/AIDS making the country run one of the most expensive anti-retroviral

projects in the globe (Blecher et al., 2016). This has made it compelling to seek different stakeholders' perceptions and attitudes on factors underpinning stigma, especially in rural areas, possibly beset with ignorance as well as the paucity of qualitative information about the disease. This researcher makes assumptions that stigma is underpinned by factors that include weaker campaigns pertaining to the disease; myths associated with the disease; ignorance about the disease; denialism; and poverty associated with the disease. The researcher also believes that if these factors are significantly addressed, stigma can significantly be mitigated if not annihilated altogether.

### **Theoretical frame - The philosophy of Ubuntu**

This study is guided by the philosophy of Ubuntu. Conceptually, the ideals and philosophy of Ubuntu are derived from the Xhosa language saying "*Umntu ngumtu ngabantu*". This aphorism is one of the cornerstone ideals of Afrocentrism that the success of indigenization and decoloniality especially in social work hinges on (Mupedziswa et al., 2019). Ostensibly, Ubuntu has been identified as the authentic indigenous African philosophy and worldview and connotes a collection of values and practices that black people view as making people authentic human beings. It advocates for humanity and interconnectedness (Mupedziswa et al., 2019; Mugumbate and Chereni, 2020). For African people, this implies a collective value of being there for one another, providing love where there is hatred and disdain, providing emotional and spiritual support for one who lacks, facilitating interdependence and interconnectedness, fostering a communitarian spirit, providing a shoulder for one to lean on, a hand to support one who is falling, and generally being of mutual assistance to one another. This researcher believes that all these values that Ubuntu holds dear are also cornerstone values of the social work profession (Segal, Gerdes & Steiner, 2007). These values also connote and emphasize human rights that the PLWHA are denied through being stigmatised. This implies that the application of Ubuntu philosophy could aid and facilitate the much-desired social work goals of emancipation such as destigmatising diseases such as HIV/AIDS.

While stigma directed at the PLWHA means hatred toward them, distancing oneself from them, failing to trust and accept them as equal human beings, and denying them humanity and dignity, as well as seeing them as a danger to the wellbeing of society (Kang'ethe (2020), applying the underpinnings of Ubuntu such as love, trust, empathy, will discourage hatred that drives stigma and stigmatisation. Further, applying trust and empathy will welcome PLWHA as normal human beings. Moreso, offering the PLWHA a helping hand, as well as a shoulder to cry on, will give them a new lease of life free from stigmatising encumbrances. This will make them live their lives with dignity and enjoy the humanity that Ubuntu guarantees.

## **METHODS**

### **Research paradigm and research design**

The study utilized an interpretative paradigm that facilitated the underpinnings of stigma to be subjectively explored and described (Claire et al. 2018). The study used both a descriptive and an exploratory design, with a case study as a specific design to investigate only a few samples for their insights, thinking, and attitudes on the role of stigma in undermining the HIV/AIDS campaign. Further, the researcher applied the philosophies of Ubuntu by being kind to the participants, handling them with trust and dignity, as well as allowing them to express themselves freely in their mother tongue. This means that the study embraced some degree of research indigenization (Mugumbate & Chereni, 2020; Chilisa, 2020; Mupedziswa et al., 2019).

### **Sample selection, data collection, and procedure**

The study adopted the non-probability method, specifically purposive sampling to pick the most suitable samples to investigate. This means that the samples were chosen based on their suitability to answer the study's research questions (Claire et al., 2018). The data collection process was cross-sectional as data was collected within a short period of time due to the motivation to cut costs. The study involved 8 participants in in-depth interviews while 25 participants were involved in 4 focus group discussions, one FGD from Alice Hospice (5 participants), 2 FGD from Lavela old age centre, one with 6 participants, and the second one with 7 participants, and one FGD with the 7 participants from the University of Fort Hare. These 33 participants gave insights into the drivers pertaining to HIV/AIDS stigma in Alice township and its environs (Claire et al., 2018). Further, data collection was carried out in the Isixhosa language as most people were Amakhosa. It was audiotaped and then transcribed by one of the research assistants. This was convenient as two of the research assistants were of the Isixhosa subtribe. Opportunely, one assistant was there to handle any debriefings in case any of the participants would need some emotional debriefings. Further, the research process respected the principle of saturation meaning that an

investigation on a theme would stop upon the subsequent participants repeating the same information. The researcher and his two research assistants also considered temperamental cues to enrich the qualitative data and saw the participants as important stakeholders collaborating in the research undertakings. This is respecting the phenomenon of indigeneity in the data collection process (Chilisa, 2020).

### Ethical and legal requirements

To ensure the study met both administrative and legal conditions, the principal researcher and one of his assistants had secured letters from their Head of Department authorizing them to conduct community engagements among different communities in Alice and its environs (Ahmed and Palermo, 2010). The principal researcher also managed to secure the participants' informed consent after briefing them on all the study's goals and objectives, as well as educating them on the ethical premise that anyone had the right to withdraw from research engagement in case they felt uncomfortable with the research questions or any process. However, no one objected, and all participants willingly signed the consent forms (Bryman, 2012). Perhaps this was motivated by the rapport that the principal researcher and his research assistants had established with most communities in Alice and its environs for a number of years they had had community engagement sessions (Ahmed and Palermo, 2010; Bryman, 2012). The researcher and his research assistants, using their richness in various social work skills ensured that the participants were professionally handled, were not hurt emotionally, treated with dignity, as well as ensured none of their human rights was violated. This connoted the application of the ethos of Ubuntu and indigenization (Chilisa, 2020; Mugumbate and Chereni, 2020). One of the social worker's tasks was to administer any debriefings in case a participant was emotionally hurt during the interview. This is to ensure the human rights of the participants.

### Research domain and justification of choice

The study took place at the end of 2016 in Alice town of the Eastern Cape province of South Africa. Alice is one of the Eastern Cape's rural towns premised in Nelson Mhlaba Municipality of Amathole District of South Africa; and consists of 42 rural villages that differ in size and population, with those near Alice town tending to be more densely populated than those far off the town metropolis. Although the researcher invoked the principle of diversity to consider in equal importance the samples that were near Alice town metropolis as well as those that were far off, the samples in the central part of Alice town purposively stood higher chances of being picked than those that were far.

## FINDINGS AND DISCUSSION

This section presents the insights of thirty-three participants of Alice town and its environs pertaining to the drivers or the underpinnings of HIV/AIDS stigma in the study domain. The first section of the findings presents the demographic characteristics of thirty-three research participants, while the second part discusses the thematic findings of the study.

*Table 1: Demographic profile of the participants*

| Method of Data Collection | Organizational affiliation                              | Participants |         | Total |
|---------------------------|---|--------------|---------|-------|
|                           |   | Males        | Females |       |
| In-depth Interviews       | Victoria Hospital                                       | 0            | 1       | 1     |
| In-depth Interviews       | University. of Fort Hare Clinic                         | 0            | 1       | 1     |
| In-depth Interviews       | University of Fort Hare (staff)                         | 1            | 0       | 1     |
| In-depth Interviews       | University of Fort Hare (student)                       | 1            | 0       | 1     |
| In-depth Interview        | South African Police Services (SAPs)<br>(Alice Station) | 2            | 0       | 2     |
| In-depth Interview        | Alice Victim Support Centre                             | 0            | 1       | 1     |
| In-depth Interview        | Community Leader  | 1            | 0       | 1     |
| Focus Groups              | Alice Hospice   | 1            | 4       | 5     |
| Focus Groups              | Lavela Old Age Centre                                   | 2            | 11      | 13    |
| Focus Groups              | University of Fort Hare                                 | 1            | 6       | 7     |
| Total                     |   | 9            | 24      | 33    |

Table 2: Thematic presentation

| Number | Themes   |
|--------|--|
| 1      | Ignorance of aetiology and epidemiological path of HIV/AIDS        |
| 2      | Weaker campaign in the rural areas                                 |
| 3      | The poverty of people in Alice town and its environs drives stigma |
| 4      | HIV/AIDS denialism   |
| 5      | Misleading information from traditional practitioners              |

### ***Ignorance of aetiology and epidemiological path of HIV/AIDS***

While the word aetiology in this context refers to the knowledge of the origin of the disease and epidemiology of how the disease spreads, study findings indicated that stigma was still at large because a larger population in the study area was still ignorant of what the disease was and how it spreads. Participants decried that the paucity of qualitative information especially in Alice town and its environs was attributed to few or no NGOs to educate people on the aetiological and epidemiological path of the disease and therefore enhance the response to the disease. Some participants, especially those living far from the Alice town metropolis were still in doubt about the aetiological and epidemiological path of the disease and therefore, opted to handle the disease with secrecy as a coping mechanism. The following sentiments attest to the above finding:

*Most of us especially those living far off from Alice's metropolis do not adequately understand the dynamics of HIV/AIDS. This has made us feel pain in our hearts when the disease is mentioned. This is why stigma is subjected to those living or suspected to be infected. This ignorance makes stigma linger longer. Our rights to know the aetiology and the epidemiology of the disease are limited.*

*We in the deeper rural areas far off Alice town are in deep trouble. Sometimes we hear there are talks in the clinics about the disease. But these are received by those who are invited. The information about HIV/AIDS to us is scanty. This makes people in the rural areas listen to the voices of traditional healers whom we are again told are misleading. What are we supposed to do? Indeed, our right to acquire appropriate knowledge about the disease is causing stigma to thrive.*

The above sentiments point out that the HIV/AIDS information relay and dissemination in Alice and its environs poses a serious lacuna that makes HIV/AIDS stigma linger longer. It was apparent that societies especially in deeper environs of Alice town lived in ignorance of the dynamics of the disease coupled with their low levels of literacy. This means that they suffer human rights deficits in accessing information about HIV/AIDS. In some of the study areas, clinics were many kilometres away making it hard for some people to access them. Further, there were few or no NGOs to spread the message of HIV/AIDS and therefore strengthen the response (Mrashula, 2017). This state of ignorance cutting across regions is exacerbated by factors such as low literacy levels and generally low socio-economic situations. In the study area, the paucity of the NGOs that would have complimented the government service delivery confounds access to information about the disease. Studies by Kajita and Kang'ethe (2017) confirmed the fact that many health challenges in many rural settings of the Eastern Cape could be attributed to a lack of health-based NGOs. The level of ignorance among many people from the deeper rural areas was also believed to be a platform of stigma and stigmatisation (Mrashula, 2017). This can be supported by a study by Nyasulu et al., (2021) that investigated factors associated with HIV-related stigma among commuter populations in Johannesburg, that found that those with low levels of education reported experiencing higher states of stigma.

### ***Weaker HIV/AIDS campaign in the rural areas***

Study participants in Alice and its environs experienced a weaker HIV/AIDS campaign infrastructure as some of their areas did not have any clinics, or the clinics were far off and inaccessible, and the area suffers the absence of or a lack of NGOs to supplement the poor government campaign machinery. This made HIV/AIDS be received with fear that motivated the thriving of stigma and consequent stigmatisation. The following sentiments attest to the findings above:

*Yes, we understand the staff in many clinics in Alice and its environs offer information and other requisite tools, but these clinics are interspersed, and one must walk many kilometres to reach the clinics. We feel left out and our rights to access HIV/AIDS information and services are undermined.*



*Here in the villages surrounding Alice town, the absence of NGOs and CBO/CBAs doing HIV/AIDS campaigns in the rural areas of the Eastern Cape has dealt us a blow in HIV/AIDS information dissemination. We appear to have no right of access to qualitative information about HIV/AIDS.*

The excerpts above suggest that people in rural areas feel that their rights to access HIV/AIDS requisite tools and information are undermined. This information gap could largely be contributing to HIV/AIDS stigma (Kang'ethe, 2020). It is compelling that the government and other stakeholders initiate or strengthen the HIV/AIDS campaign infrastructure in rural areas to address the challenge of HIV/AIDS stigma. This calls for societies to widen their safety nets to fill in these gaps, especially in information dissemination, care, and prevention. A study in the United States of America by Murry (2015) recommended that since rural communities face a dearth of requisite healthcare services, it is important that close kinship, community ties, and informal support systems are strengthened to offer support to people living with HIV/AIDS. Although people in ubiquitous corners of South Africa due to wider coverage of information dissemination through print and electronic media are increasingly becoming knowledgeable about HIV/AIDS, and the country has achieved the first of the WHO 90-90-90 targets (UNAIDS, 2017), paradoxically, scores of people in deeper rural areas are bereft of adequate information about HIV/AIDS (Taukeni and Ferreira, 2016). This means that the right to information access is emasculated. This leaves room for stigma and stigmatisation about the disease to thrive.

### ***The poverty of people in Alice town and its environs drives stigma.***

Virtually all the study participants in Alice and its environs were in accord that an inextricable relationship between incidences of poverty and the prevalence of HIV/AIDS exists, with stigma thriving relentlessly. Many participants decried that most rural parts of the Eastern Cape province were largely poverty-stricken and laden with ignorance, the condition forming a fertile ground for viral proliferation and increased incidences of stigma surrounding the disease. The following sentiments bear testimony to the finding above:

*The inextricable relationship between higher incidences of poverty and the prevalence of HIV/AIDS is utterly scary. Therefore HIV/AIDS will remain a stigmatized disease.*

*It is the sheer lack of education on the aetiology and the epidemiology of the disease in rural areas that make the disease both dreadful and stigmatised.*

The finding above is echoed by Nkalane (2017) who established that an interplay between incidences of poverty and the prevalence of HIV/AIDS exists that further encouraged HIV stigma. Further, a striking characteristic in many research domains pointed to more women than men bearing the brunt of both poverty and HIV/AIDS. This attests to the characteristics of both feminisation of poverty; and feminisation of HIV/AIDS, with both phenomena associated with stigma (Kang'ethe & Munzara, 2014). Incontrovertibly, empowering the people of rural areas with requisite information about the aetiology and epidemiology of the disease is an intervention that can help them understand the dynamics of HIV/AIDS and possibly help reduce its stigma. This will also enhance their rights to sound prevention and response. Indeed, stigma, whether external (the actual experience of discrimination by unfair treatment) or internal (felt or imagined shame and expectation of discrimination), prevents individuals from disclosing their status as well as makes them shy from accessing health care services (Mbonu et al., 2009). This further mirrors studies by Mrashula (2017) in the Cofimvaba region of the Eastern Cape of South Africa that established an inextricable relationship between incidences of poverty and escalation of HIV/AIDS, with the environment motivating stigma surrounding the PLWHA. A similar study conducted in Tanzania reported that poverty, less education, and living in rural areas were factors associated with high HIV-related stigma (Amuri et al., 2011).

### ***HIV/AIDS denialism***

Most of the participants established HIV/AIDS denialism as a factor that increased the state of stigma and discrimination. This, they echoed was a coping mechanism. This made people not only drag their feet for testing to know their status but also dissuaded them from accessing most of the services that facilitated positive living. This also obscured people from disclosing their status as a way of strengthening the HIV/AIDS campaign and increasing the pace of positive living. The following sentiments bear testimony to the finding:

*People adopt denialism because of the pains that those who are known to be living with HIV/AIDS undergo. Societies are still not ready to come to terms with accepting and normalizing the disease. The disease is largely stigmatised.*

Unequivocally, denialism is a big blow to the HIV/AIDS campaign in Alice and its environs and forms a palatable environment for states of stigma. While denialism is a huge driver of stigma as it facilitates denialism, both manifest an egg-chick relationship, where each is a cause and a result of the other (Mall et al., 2013). Studies in

South Africa revealed that stigma-driven denialism is a significant barrier to HIV testing (Gilbert & Walker, 2010). Further, low levels of testing are believed to increase HIV infections as it interferes with HIV counselling, prevention, diagnosis, and treatment efforts (Jurgensen et al., 2013; Stangl et al., 2013). Usually, fear of stigmatisation, discrimination, and breach of confidentiality result in low uptake of HIV testing services (Zou et al., 2013; Zhang et al., 2014). A study by Nobuhle (2017) contended that denialism is a factor that proliferates the state of stigma and discrimination as it dissuades people living with HIV/AIDS from disclosing it. Disclosure is important in the HIV/AIDS campaign because people tend to elicit confidence from hearing HIV/AIDS messages from those who have publicly disclosed it (Kang'ethe, 2020). Inopportunistly, lower states of the disclosure on account of stigma and stigmatisation have dire consequences in that many people have their health worsen and resort to asking for assistance when it is too late. Cases abound where many people living with HIV/AIDS died in Botswana in the first decade of the 21<sup>st</sup> century (2001-2010) when they consulted and sought clinical assistance in the wee hours of the HIV/AIDS disease (Kang'ethe, 2012).

### **Misleading information from traditional practitioners**

Virtually all the study participants in Alice and its environs indicated that despite their positive contribution in the domain of HIV/AIDS, traditional practitioners such as traditional healers, spiritualists, and diviners/ Sangomas, were contributing to stigmatising the disease. This makes the disease a complicated one, with the phenomenon presenting opportunities for significant stigmatisation. The following verbatim sentiments bear witness to the findings above:

*Unstructured HIV/AIDS campaign in rural areas has left a lacuna that the traditional practitioners are filling, usually concocting lies so that they may remain relevant to the trade. The rights of the people to access rightful information are largely undermined.*

*The information gap between biomedical practitioners and these traditional practitioners is providing a rich environment for stigma to thrive.*

Ideally, the presence of several players presenting different information packages to South African communities brings confusion and breeds a dilemma of wondering which information is reliable. This provides a fertile ground for stigmatisation of the disease (Mngqundaniso and Peltzer, 2008). This is because traditional practitioners are bent on misconstruing the information given by biomedical professionals (Mngqundaniso and Peltzer, 2008). This mirrors research findings from Botswana that underscored the role of the traditional healers in concocting lies about HIV/AIDS with people being presented with two sets of separate truths about how to tackle HIV/AIDS (Kang'ethe, 2012). Ironically and paradoxically, communities especially in rural areas are likely to hold and value the messages and services of the traditional practitioners in equal measure, or even more, if not in tandem with the messages from the biomedical practitioners. Perhaps this is because traditional practitioners such as healers are the first to be called for help when illness strikes the majority of South Africans (Kang'ethe, 2012). These practitioners win the souls and minds of many people because they promise what people want to hear. For example, they promise to make people rich, bring back lost lovers, afford them the security of their wealth, protection from evil people and spirits, and enhance people's sex life by helping them enlarge their penis and facilitate vagina-tightening spells (Mngqundaniso and Peltzer, 2008). When these traditional practitioners cause people not to seek medical assistance in time, this means they compromise their rights to access health timeously.

### **CONCLUSION**

It is central that robust research is advanced to bring to the fore all the drivers of stigma if HIV/AIDS is to be annihilated or significantly mitigated in South Africa. Soliciting the insights of different stakeholders in every society serves an indigenous approach and is likely to assist in the programming of interventions to address the state of HIV/AIDS stigma. It is also important that the government work hard to ensure collaboration as well as synergy between different stakeholders in the HIV/AIDS arena. This is to expeditiously ensure the centralization of all the HIV/AIDS messages and enrich the rights of the people to a stigma-free generation. Social service professionals such as social workers are central in managing such a campaign endeavour.

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