Embodied, Embedded and Educated: How Everyday Heroes Strive to Save Lives during a Pandemic

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Abstract

Drawing on an ethnographic study of the HIV/AIDS pandemic, we explore how ordinary people make extraordinary efforts to convince others to comply with health authorities' advice to change their behaviour. Theories of heroism and embodied health movements inform our typology consisting of four distinct types of everyday heroes. Everyday heroes adopt a variety of actions, uniquely drawing on their embodiment of the illness and embeddedness in the local context. The 'national role model' builds a personal brand promoting beauty with a purpose, while the 'national entrepreneur' assembles resources and builds support networks and institutions. The 'local caregiver' offers face-to-face support to the diseased and afflicted, while the 'local entrepreneur' creates non-risky health practices to replace risky ones. A significant finding is the heroes' courage and creative self-educational work, through which they find their own ways to translate medical knowledge into the local vernacular and practice.

Keywords

Everyday heroes, embodied health movements, pandemic, hero actions, self-transformation, HIV/AIDS

Introduction

Public health marketers have long known that medical regimes entailing socially undesirable mandates and biomedical treatment are hard to implement (Rothschild, 1999) and associated with misinformation that undermines trust in medical and political authorities (Mbonu et al., 2009). Pandemics destabilise society, and well-known market processes may not function well. The COVID-19 pandemic has shown that some people, even when faced with a potentially deadly illness, choose non-compliance over authorities' life-saving measures.

Although the marketing literature has theorised how subcultures create their own health value systems (Thompson and Troester, 2002) or oppose medical expertise to promote alternative health practices (Thompson, 2005), knowledge is limited on how everyday people,

themselves ill, assume leadership to influence others to accept the advice and treatment promoted by medical experts and authorities. We address this gap with the following research question: How can everyday people, who are not particularly influential by virtue of professional experience or social privilege, acquire a social position sufficient to convince (even resistant) others to comply with health authorities' advice to change their behaviour during a pandemic?

Research on embodied health movements helps explain why everyday individuals believe their experience of an affliction gives them the right and responsibility to help others (Brown et al., 2004). Their actions draw credence from their first-hand knowledge of the illness and their bodies' response to treatment (Maguire et al., 2004). Sharing illness experiences in support and self-help groups is the first stage of forming a collective illness identity, giving individuals a voice in the marketplace and positioning them to both challenge and collaborate with scientists and health professionals (Brown et al., 2004; Zoller, 2005).

We explore this issue through an ethnographic field study in Botswana during the global HIV/AIDS pandemic. Botswana was experiencing a national health crisis as the second-most HIV/AIDS-infected country globally (UNAIDS, 2017). Sub-Saharan Africa had fallen behind the rest of the world in terms of HIV/AIDS treatment and health services. Hence, this was an unprecedented situation, and health authorities imposed many constraints to regain control and stability (Nguyen, 2009). Overwhelmed by foreign (Western) biomedical marketing and expertise, the uptake of HIV treatment remained slow. Medical anthropologists and sociologists claimed that a lack of cultural fit and grassroots involvement undermined the Africa people's trust in the treatments (Swidler, 2006). It took several years for local entrepreneurs to mobilise community support groups (Zuyderduin et al., 2008) and local individuals who could convince others get treatment and stop the virus from spreading.

Our findings suggest that during a pandemic ordinary people engage in extraordinary efforts to help others. Our study provides detailed accounts of how HIV-infected individuals embarked on a courageous personal journey of self-transformation and went public with their illness status to help save others' lives. We develop a typology consisting of four distinct types of everyday heroes, defined by their hero actions and the social arenas in which they work. Our study shows that everyday heroes are not homogeneous. Both personal and situational factors shape and enable everyday heroes to mobilise embodiment and embeddedness, providing them with influence (Frisk, 2019). Their actions are complicated long-term social projects (Glazer and Glazer, 1999), as they penetrate social, economic and political institutions and eventually change them (Burchardt, 2016).

These findings contribute to the marketing literature in several ways. First, we offer a typology of everyday heroes during a pandemic, where everyday heroes embody the experience of a life-threatening disease and strong social stigma (Parker and Aggleton, 2003). Embodied illness experiences are involuntary, prolonged and charged with negative emotions and uncertainty and associated with impaired physical, psychological, social, financial and day-to-day functioning in everyday life (Royer, 1998). We theorise the different strategies everyday heroes use to help others despite such challenges. In doing so we extend existing theories of creative ways people empower themselves and others in the marketplace (Patsiaouras et al., 2018). We also contribute to the theorisation of various roles heroes can assume in a market situation with extraordinary constraints (Sobande et al., 2020) and mandates from health authorities impacting everyday social interactions and practices.

The article proceeds as follows. First, we review the HIV/AIDS Positive Living Movement. We review hero theory and conclude with a definition of everyday heroes and relate this to elements in Embodied Health Movements. We explain the context and method of

our study and how they allow us to develop new theoretical insights. Finally, we present our findings and relate these to marketing research.

The Positive Living Movement during the HIV Pandemic

Living positively with HIV/AIDS involves knowing and publicly disclosing one's HIV+ status, maintaining a positive attitude towards self and others, adhering to medical advice and treatment, eating a healthy diet, avoiding alcohol and cigarettes, maintaining social activities, sharing one's hopes and fears with others, being sexually faithful and condomising (Benton et al., 2017; Dilger, 2001). The 'positively living' slogan emerged from the gay and Black civil rights movements in the USA in the 1970s (Dilger, 2001). However, the Positive Living principles — a set of moral, physical and social practices — are global and cross different political, social and economic contexts.

While global, the Positive Living principles needed to be contextualised. During the 13th International AIDS Conference in Durban, South Africa in 2000 it became clear that 'for African problems, African solutions are needed' (Dilger, 2001). Until then, most HIV/AIDS health intervention approaches had been transferred to the African context from Europe and the USA without adequate consideration of the possible cultural differences between the original and prospective target groups (Swidler, 2006). A needs assessment among HIV+ people in Botswana (2000) revealed a great need for social support. In response, a grassroots support group (COCEPWA – Coping Centre for People living with HIV/AIDS) implemented buddy training programmes to educate and assist local individuals to help others in their communities get treatment and stop the virus from spreading (Zuyderduin et al., 2008). One of the founders explained the programmes:

> To become a buddy, COCEPWA coordinators select a healthy HIV-positive member who undergoes a week's training course on: effective communication skills, the basics of the disease, medicines, nutrition, dealing with violence and alcohol abuse and positive living. Buddies were then linked up with their 'clients' for a period of up to six months and were required to maintain regular contact with them – up to three times a week….Buddies also need counselling, they carry heavy loads, so they need time to heal. They have their own regular support group meetings for this. (The New Humanitarian, September 2003, https://www.thenewhumanitarian.org/fr/node/214213)

Similar buddy systems were implemented throughout the region, usually with support from health authorities and non-government organisations (NGOs) (Dilger, 2001).

Who is the everyday hero?

A hero's journey starts with a disequilibrium and a departure from the status quo (Hirschman, 1989). The change of setting and the subsequent self-transformational work enable the hero to return to their origin setting and to convince others of the new insights and experiences gained (Sonnenburg and Runco, 2017).

In a pandemic, a hero's journey starts with an unwelcome health diagnosis rather than an epiphany or disruptive nudge in everyday life (Hirschman, 1989). Especially with sexually transmitted diseases (e.g. HIV/AIDS), the departure from the status quo disrupts one's self-image, entailing shame, blame and social exclusion due to stigma (Parker and Aggleton, 2003). Those who embark on a hero's journey in a pandemic must convert their embodied illness sufferings into sharable self-transformation stories (Burchardt, 2016). Heroic self-transformation illness stories include accepting the diagnosis and afflicted status, framing adherence to medical treatment as a personal success story and achievement and linking the

self-transformation process to involvement, training and listening to others' testimonies in local support groups (Burchardt, 2016). Some self-transformation stories are carefully crafted for public settings and mass media, aiming to influence decision- and policy-making (Dohan et al., 2016); others are informal and incorporated into ordinary grassroots-level conversations (Sharf and Vanderford, 2003). Notably, good storytellers connect with audiences through confessions, allowing the audience to identify with them. By telling and retelling their stories to different audiences, they come to personify both proof and hope of surviving the illness along with the accompanying stigma and prejudice. Stories of heroic self-transformation travel across institutional circuits through local support groups, NGOs and national and international stakeholders involved in large-scale health interventions (Burchardt, 2016).

Courage is central to heroism and is based on a conscious choice to help others despite knowledge of a risk of harm (Glazer and Glazer, 1999). However, acts of bravery are typically less calculated (e.g. jumping into the ocean to save a drowning person). Brave acts are extraordinarily heroic but impulsive, while courageous heroism implies long-term dedication (Kinsella et al., 2017). Heroic actions involve new knowledge and creative new ideas that challenge the mainstream market consensus. Frisk (2019) encourages us to ask why some individuals act heroically while others do not. This question invites us to reflect on the interplay of situational versus personal factors in heroic action. Embodied heroes do not emerge from nowhere; rather, they benefit from their communities' accumulated cultural and social capital. Indeed their deep contextual understanding provides them with legitimacy and trust. Glazer and Glazer (1999) show how employee whistle-blowers and environmental crusaders build on their identity as grassroots community members when confronting opposition and formulating agendas. They argue that it takes a village to make a hero and that everyday 'heroism derives meaning from everyday life in constant social construction and reconstruction processes' (Frisk, 2019: 94).

Accordingly, we define everyday heroes as ordinary individuals who help others in extraordinary ways despite the risk of personal harm (Frisk, 2019; Kinsella et al., 2017; Sonnenburg and Runco, 2017), who demonstrate the ability and motivation to accumulate and share evidence and expertise (Burchardt, 2016; Glazer and Glazer, 1999), who offer creative ideas that challenge mainstream marketplace norms (Glazer and Glazer, 1999; Velikovsky, 2017; Hirschman, 1989) and who identify with others in their local community (Burchardt, 2017; Glazer and Glazer, 1999). These hero characteristics align with concepts from the embodied health movement theory, which we present next.

Embodied Health Movements

Research on embodied health movements (EHM) suggests that illness experiences qualify a person to become leaders in educating others about their illness and possible treatment (Maguire et al., 2004). EHMs work with three agendas, such as: challenging healthcare regimes; providing innovative hypotheses based on embodied experiences with the healthcare system and the disease; and pushing for democratization and inclusion in treatment and health care provision (Brown et al. 2004). EHMs typically collaborate with scientists and health authorities as they can not afford to alienate themselves from their communities and public health institutions.

Through EHMs, individuals can build politicized embodied illness identities that enable participation in the political discourse regarding structural inequalities, distribution of social power, and causes and treatment of a disease (Brown et al. 2004). Illnesses include widely recognised forms, such as asthma and breast cancer. In contrast, contested forms are not adequately explained by existing science or have disputed explanations such as HIV/AIDS when it first emerged. In contested forms of illness the embodied experience often differ from its medical understanding, and activists in EHMs striving to influence power elite

opponents often organise public demonstrations and lobby government representatives for better health citizenship rights. Furthermore, tactics in persuading others to join their cause include taking on leadership roles within support groups, and acting as lay experts about biomedical aspects of the disease (Zoller 2005). They can also act as community role-models of desirable health behaviours by providing living proof of lifestyle changes needed to combat the disease (Zeuderduin et al. 2008).

We apply these insights and concepts from the EHM literature to explore how everyday heroes work in a situation where serious health ramifications and social stigma exacerbate the personal risk and effort involved.

Methodology

Context

In most of Africa, the HIV/AIDS pandemic went untreated until the 13th International AIDS Conference in Durban, South Africa, in 2000. In 2001, the UN Assembly declared HIV/AIDS in Africa a global humanitarian emergency. In Botswana, the situation was particularly dire and then president of Botswana – Festus Mogae - declared a national emergency and made an impassioned plea for international assistance. Subsequently, an international consortium mobilised a massive health intervention in Africa to provide free and easier access to HIV/AIDS health facilities and treatment.

The Ethnographic Field Study

This study draws on a recurring HIV/AIDS event occurring in Gaborone, Botswana's capital. In 2002, NGOs in Botswana initiated HIV/AIDS beauty pageants to elevate everyday people as living proof of the benefits of the Positive Living Lifestyle. These pageants recruited contestants nationwide from BONEPWA (Botswana Network for People Living with

HIV/AIDS), whom they trained in public speaking, health buddy work and HIV/AIDS as a biomedical illness. In preparation for the pageants, the participants attended workshops about how to enact social roles and advocate for programmes to help overcome the national crisis. In addition, a panel of judges interviewed the contestants about their knowledge of the biomedical and sociocultural aspects of the disease and their plans to act as social role models of the Positive Living lifestyle.

The pageants were big events attracting multiple actors engaging in multiple activities in one place for a certain period of time (Spradley, 1980). The research team thus started to prepare for the fieldwork half a year before arriving at the Mr. HIV/AIDS Positive Living pageant in April 2006. In November 2005, the second author attended a global HIV/AIDS health conference and conducted exploratory interviews with key informants among the organisers and local NGOs, maintaining e-mail contact to learn about the planned activities for the 2006 pageant. The research team also watched news media coverage and interviews with previous contestants and winners of the pageants. Inspired by similar big-event marketing research (Kozinets, 2002), we included an experienced ethnographic filmmaker on the research team. Our ambition was to produce enough footage for a later videography and to document as much as possible during the event. Our primary focus was on interviewing the contestants and observing how they participated in activities during the event. We expected that the pageant would be the only opportunity to talk with them at length. In March 2006, the second author and a filmmaker, returned to Botswana for the pageant.

The research team video-recorded the face-to-face interviews and most pageant-related events. Whenever possible, a local fluent in Setswana assisted with the interviewing. Precious, Miss HIV Stigma Free 2005, played a crucial role in the fieldwork. She was a central figure in the 2006 male pageant and leveraged her substantive experience and insights into HIV/AIDS advocacy. The team also participated in social activities offstage when

contestants interacted with their families, friends and colleagues and accessed their medications. The informants included pageant contestants, HIV/AIDS activists, NGO leaders, politicians and governmental health officers (Table 1). Together this 'open-minded' participant observation approach allowed us to capture the overall atmosphere at the event, structural elements (such as power relations), popular discourses taking place in different forums such as workshops, and different personalities making their mark on the event.

Insert **Table 1** – Informant details

The data comprised 25 hours of video and 320 pages of transcribed interviews, excluding field notes, along with mass media interviews with informants and archived videos from pageant events made on behalf of NGOs and public health authorities. The team followed up on several informants with e-mails and repeated field visits. In 2008, the project hired a Botswanan PhD student in public health at the University of Sydney as a research assistant. He visited the field in 2009, 2010 and 2013, conducted follow-up interviews with lay experts and four of the original informants — Amogelang, Donald, Paul and Thomas — and transcribed the interviews. Throughout the project, reports by national and international stakeholders, mass media event coverage, interviews with significant actors, columns, videography films and e-mails with key individuals from grassroots organisations were collected and analysed (see Table 2).

Insert **Table 2** – Archive data sources

Data Analysis

Videoed interviews and field footage, transcribed interviews, written field notes, documents, public reports and media coverage were coded and analysed using constant comparative

analytic techniques (Glaser and Strauss, 1967). It became apparent that the everyday heroes adopted different strategies to influence and educate others.

From our sample of 10 informants, we chose four everyday hero journeys that typify core characteristics and show variations in everyday hero actions and their target arenas. The variations are organised along two dimensions (Table 3). The first dimension characterises hero actions, which may aim to change social norms or build new institutions. The other dimension depicts various social arenas in which everyday heroes convey their stories and enact their roles. Some work with national and international stakeholders to influence health policies, while others work in local communities or through face-to-face exchanges. Each hero type reflects these two dimensions, and each journey unfolds through the hero action elements identified by theory: self-transformation journey, sharing evidence and expertise, challenging marketplace norms and identifying with and building community. We drew on the hero literature to develop a definition of the everyday hero, which we applied as a scaffold to structure our analysis of hero actions. The four hero types are theoretical ideal types enabling us to disentangle and accentuate variation in how our informants enacted the everyday hero role. All 10 informants can be placed in one of the cells with some overlap. The four illustrative cases clearly fit the typology.

Findings – A Typology of Everyday Heroes during the HIV/AIDS Pandemic

The everyday heroes in our study follow the traditional hero journey from departure to initiation and return (Sonnenburg and Runco, 2017). The self-transformation journeys we observed started with a serious illness diagnosis, and in many cases the subsequent self-transformation journey took years. However, the collective sharing and sense-making facilitated by the buddy programmes initiated their departure on the heroic quest (Zuyderduin et al., 2008). Next, we present a typology of four different everyday heroes to illustrate the

various ways they acquire a social position, allowing them to help others within their community change their behaviour during the pandemic. Crucially, all four everyday heroes embody the illness and mobilise their personal resources and deeply embedded knowledge of local norms and beliefs.

The *national role model* builds a personal brand, leveraging its impact to change social perceptions and norms both nationally and internationally. *The national entrepreneur* acquires political skills and succeeds in mobilising national and international resources to build grassroots support for the ill. The *local entrepreneur* creates new social arenas for the community so that others can avoid risky behaviour and regain their dignity and hope. The *local caregiver* disarms local taboos by creating stories that translate biomedical knowledge into everyday practices (Table 3). To bring these hero types to life, we draw on illustrative cases (Precious, Donald, Paul and Otsile) from our data.

Insert Table 3

The National Role Model

The national role model exemplifies how an individual without a privileged social position can become an educator and leader to the power elite within a given social setting. The purpose of national HIV/AIDS beauty pageants was to give the winner a celebrity megaphone and social position for disrupting and changing established 'public norms, policies and social structures' (Zoller, 2005: 360). Celebrity role models also enjoy legitimacy among the target group, who can identify with them. In 1991, when Magic Johnson went public with his HIV+ status, he changed the image of people living with HIV/AIDS. Following his disclosure, testing and antiretroviral treatment rates accelerated dramatically among African American males in the USA (Brown and Basil, 1995). The case of Precious as the embodiment of a

national role model is detailed below. It shows how everyday people with no celebrity role to begin with can also become role models, thus helping others change their behaviour.

Self-transformation journey. Precious's life story points to a rebellious streak. She admits to evolving from the 'black sheep' in her family to a positive role model and leader on a large scale. She reports being a teenage gang leader, disappearing, sometimes for days, drinking and partying, a life her mother described as 'off-leash'. After high school, she left her tiny remote village and earned a diploma in commercial administration at Technical North-West University in South Africa. She pursued a career as a legal secretary and followed a free-spirited urban lifestyle. Upon becoming ill, she quit her job and moved back in with her mother in Botswana.

Although she tested HIV+ in 2000, it took her five years to recover enough to enter the Miss HIV Stigma Free beauty pageant. In those intervening years, she came to work for the Coping Centre for People Living with HIV/AIDS (PLWHA) and was inspired by its pioneering work in educating Botswanans about HIV/AIDS prevention and treatment. She received extensive training in speech writing, public speaking and handling the press. In her spare time, she embarked on a self- and family-funded personal crusade, travelling around Botswana to raise HIV/AIDS awareness. She also acted as Botswana's first 'buddy', someone who pairs up with another person newly diagnosed with HIV and advises them about treatment and lifestyle modifications based on acquired knowledge and lived experience of managing the disease (Marino et al., 2007).

Hero actions. When Precious entered the 2005 Miss HIV/AIDS Stigma Free pageant scene, she had become a lay expert on how ordinary people with HIV/AIDS fared in Botswana.

> When I was on the stage and talking to the judges, I knew. They wanted to know about the most important thing – the knowledge about HIV and AIDS and the other

> important thing – about confidence…. Of course, I [also] practiced and practiced by myself in the toilet and looking at myself in the mirror (interview, 2006).

After winning the pageant, Precious became one of the most vocal HIV/AIDS spokespersons in Africa under her personal brand 'Beauty with a Purpose'. She used her newfound celebrity to personify socially desirable attributes, creating new associations to PLWHA. After her Miss Stigma Free reign, Precious aspired to become a member of parliament, stating that she would go to

> the president or the minister of health to advocate for PLWHA…We bear the witness of living with HIV and AIDS. We can be lay counsellors, and we can even go to schools. We are the people who can prevent the spread of HIV and AIDS by telling the students or young people about how it is living with HIV and AIDS — because we will be sharing our own experiences (interview, 2006).

Precious died of complications related to her HIV+ status in December 2006. Despite reigning for only 15 months, she gave many interviews to the local and international press, starred in a documentary about her life on Botswanan television and travelled to London to be part of a BBC series about HIV/AIDS. As a national role model, she occupied public performance spaces (often created by her), where she encouraged Botswana's socio-political elites to show leadership by getting tested for HIV/AIDS and publicly adopting the Positive Living lifestyle. Below, we present excerpts from a speech given by Precious to a group of village chiefs and villagers in April 2006. Few dared to raise the topic of HIV/AIDS with village chiefs, as people of higher rank would 'rather die than publicly admit that they have the disease' (Donald, interview, 2009).

Immaculately dressed in a business suit, Precious exuded an aura of authority, focussing on her audience and barely glancing at her manuscript. She began by presenting herself as beautiful, HIV infected and socially responsible.

> I am a very beautiful woman, and I'm very proud of that fact — and I'm not even scared to let the public be aware of how beautiful I perceive myself (applause from the audience). [That's] why I took part in that beauty contest [for HIV+ women].

Spontaneous cheering and applause signified that Precious appeared to contradict the negative preconceptions about PLWHA. As a national role model and brand, she used her social position and creativity to challenge even the kings and chiefs. Using a Setswana saying, Precious elevated the chiefs to local kings, emphasising that kings must be exemplary and socially responsible leaders.

> We know that as chiefs, they have high accountability to and for the communities that they lead. There is a Setswana saying that goes 'kgosi ke kgosi ka batho' [*which translates to a king is a king by its people*] and 'lefoko la kgosi le agelwa mosako' [*meaning the king's words need to be given respect*]. This totem, ladies and gentlemen, teaches us that the king/chiefs have many challenges on their hands. (video, April 2006)

Precious built her personal brand 'Beauty with a Purpose' on years of field experience and training, enabling her to interact smoothly with national and international stakeholders in the health care intervention and expanding perceptions of PLWHA's resources and potential to help others. The activities described above go beyond everyday information sharing; 'Beauty with a purpose' made hitherto impossible associations between being HIV positive and a dignified, beautiful, responsible and courageous public spokesperson. Her brand was

particularly effective in addressing institutional and cultural leaders. Precious made her voice heard in the marketplace conversations both nationally and internationally.

The National Entrepreneur

The national entrepreneur creates support systems by building bridges between local and global stakeholders during the health intervention, creating value through well-known entrepreneurial qualities, such as the ability to rally support and assemble resources (Baker and Nelson, 2005). Indeed, the national entrepreneur obtains socio-political and institutional legitimacy and authority as a local expert, for example, on the HIV situation in Botswana. Further, the national entrepreneur displays an ability to 'create something from nothing' (Baker and Nelson, 2005).

Self-transformation journey. Donald was among the first in Botswana to go public with his HIV+ status: 'On the 24th of November 1993, I declared it through the radio and television'. In 1993, Donald departed from his normal life as a farmer and lorry driver by becoming a delegate at hyper-politicised HIV/AIDS conferences in the USA and Western Europe. There, he learned about the staggering HIV/AIDS macro-statistics, the highly prevalent and politicised HIV/AIDS activism in the USA and how governments in other countries were addressing the disease. He realised he wanted to 'go back to Botswana and "educate them" [the Botswanans]'.

Hero actions. National entrepreneurs like Donald strive to ensure that the afflicted receive support in adopting a complex, foreign medical treatment regime (Maguire et al., 2004). Donald's hero actions manifested in his role as the founder and leader of BONEPWA. It became a platform and social arena for him to cooperate with government institutions to design and implement HIV/AIDS health programmes for local support groups, limit mother-to-child transmission and secure the well-being of HIV/AIDS orphans. Donald explained how

he and his team developed the first HIV/AIDS pageant for men to recruit male role models and opinion leaders for Positive Living.

> What about men? Why are they not supporting the project? What is the problem?… So, we said let us come up with an HIV/AIDS beauty pageant for men… What we have to do is to encourage these ten young men… and the one who gets the crown as Mr. Positive Living. We have to really organise ourselves and find funds, where we can take him [the winner] around, give him the allowance every month, help to establish a website for him so that people can now [submit] questions, and he will be answering from that website (interview, 2006).

The pageant immediately became a hub event, attracting national and international donors and the media. In a context of denial, the pageant contributed to rendering HIV/AIDS visible and disproving many of the associated stigmas.

Donald used BONEPWA as his platform to strategize with other activists, create events and collaborate with multiple actors at different societal levels. The organisation developed into a national institution that has enabled many support agencies for PLWHA. In 2006, he realised the potential of the Web for disseminating information, illustrating his visionary capacity as a national and global institutional entrepreneur. Donald had the capacity and social bandwidth to translate and implement the ideas and policies he internalised during visits to international HIV/AIDS events. He created value for the entire HIV/AIDS ecosystem in Botswana by assembling and connecting actors and resources from multiple social levels and sectors. The institutional platforms he created enabled him to advocate for target-group interests and treatment and support needs.

Operating with extremely limited resources, he built national-level institutions and action programmes. He mobilised his international exposure to the HIV/AIDS health

movement, when most Botswanans were still ignorant. The ability to step out of one's community and internalise a cosmopolitan orientation is crucial to earning local legitimacy (Burchardt, 2016; Glazer and Glazer, 1999). The buddy network BONEPWA earned him grassroots legitimacy as a national leader and watchdog status such that politicians listened to him when making health policy decisions. Consequently, the HIV/AIDS support networks Donald helped build became permanent features in combatting the pandemic.

The Local Entrepreneur

The local entrepreneur risks personal harm and loss of social status by creating and personally displaying stigmatising behaviour as an alternative to well-established risky community behaviour (Joachim and Acorn, 2000). In doing so, the local entrepreneur builds new social community arenas that facilitate new, less risky behaviours as well as new social arenas that integrate the afflicted with others.

Self-transformation journey. Otsile was the first to admit to being HIV+ in Old Naledi, an extremely poor, crime-ridden slum on the outskirts of Gaborone. The suburb was known for its intolerance towards PLWHA. Otsile explained his prior resentment for PLWHA and the extent to which he had changed:

> I wouldn't be caught dead standing next to one [HIV+], let alone share the same street with them or [walk] where they had walked!… Now, since I have more information about HIV, I know that a person living with HIV and AIDS and a person that does not have HIV are the same people. The difference is the other person infected with HIV has an awareness of [having] HIV, but they are all the same. (interview, 2006)

Otsile understood that disclosing his HIV+ status put him at grave risk because, by implication, others within his immediate community could no longer deny their susceptibility. 'So, I wanted to set myself as an example to other people… not to be fearful, but rather for

them to know their status and be empowered' (interview, 2006). Yet, not everyone accepted Otsile's disclosure. He is a fit, muscular young man, inconsistent with the traditional image of an HIV/AIDS victim. Exhibiting his lay expertise, Otsile elaborated: 'They think an individual who is HIV+ has to show symptoms, such as visible weight loss and visible sores and ulcers. However, I do show them that an individual with HIV can be asymptomatic and healthy looking' (interview, 2006). His doubters were only convinced after seeing his medical report, illustrating that evidence of medical expertise universally conveys authority (Cassell, 2005).

Hero actions. Otsile informed others that his healthy appearance provided compelling evidence that HIV/AIDS was not necessarily a death sentence, that treatment is effective and that others should get tested. Through his transparent medical regime and lifestyle changes, Otsile embodied the Positive Living lifestyle.

He boasted that his actions led his male friends to give up high-risk living. Tanner et al. (2008) propose that people serving as role models for others have a greater tendency towards pro-social behaviour. Otsile attributed his success to his ability to create attractive alternatives to excessive drinking, a behaviour associated with unsafe sex. He started a football team, which involved bi-weekly training sessions and regular region-wide competitions. With his mates, Otsile built a makeshift gym from abandoned car parts: an axle became a barbell, a wheel hub a five-kilogram weight, with car seats for breathers between supersets. Regular exercise affirmed his commitment to behavioural change and his role-modelling of Positive Living.

Otsile seized the opportunity at community events to educate others about HIV/AIDS, trying to remove barriers to medical treatment. He served as proof that the therapeutic lifestyle works. This target group would likely not have benefited from the health care intervention without Otsile's commitment to advocacy. Everyday heroes in marginal

subcultures occupy a unique position to normalise new behaviours and activities. Their credibility lies in their capacity to provide living proof and build dignity and trust in the health intervention locally.

The Local Caregiver

The local caregiver engages in micro-social exchanges, such as home visits with fellow afflicted to offer medical supplies and emotional and knowledge support. These everyday heroes boost people's spirits by reminding them they are not fighting HIV/AIDS alone. By combining knowledge of local norms and values with astute observations to create messages to soften resistance to treatment, the local caregiver creates emotional, social and utilitarian value with and for others (Akman et al., 2019).

Self-transformation journey. When asked how many children he had, Paul asked whether that meant 'all in all'. He said he had six children with as many girlfriends, explaining that he used to be 'gay and carefree… [where] a lot of chicks were all around'. After his HIV+ diagnosis, he 'started researching for a proper perspective [on my lifestyle] and my God; he gave me the ability to handle myself'. Paul shifted from a fun-filled and carefree lifestyle to spending his days doing whatever he could to ease the lives of those diagnosed with HIV, their relatives and friends. This commitment to others' well-being became apparent in his pageant aspirations. He viewed Mr. Positive Living as a platform to become an inspirational role model with whom people would join forces to 'outsmart' the virus: '[Y]ou know that as smart as the virus is, we have to be even smarter' (interview, 2006).

After recovering from a long period of debilitating HIV/AIDS-related illnesses, Paul chose not to return to his job as a police officer. Instead, he worked for a government-funded organisation offering home-based care to the HIV/AIDS afflicted. He often travelled long

distances, delivering medicine and groceries and sharing information about arresting the disease. An international NGO gave him an 'AfricaBike', enabling him to make as many as five visits per day. As a Western aid worker noted, 'Giving an African a bike is like giving an American a helicopter' (Madden, 2010). Paul's outreach work made him a much-loved resident of Bobonong, an arid, sparsely populated area about 400 kilometres from Gaborone.

Hero actions. Paul created value by positively casting aspects of the disease and its disruptive impact on everyday life. He minimised the seriousness of HIV/AIDS by framing it as one of many pestilences throughout history.

> As much as many other illnesses are being handled that are brought by nature, this is one of the natural catastrophes. You see? I don't find it any different from TB, high blood pressure, and some other chronic ones – no. To me, it's just the most present virus. (interview, 2006)

Similarly, he equated anti-retroviral treatment (ARV) regimes and everyday eating: 'You know you are eating food in order to live. So why not take ARVs likewise?' (interview, 2006).

Paul also appealed to others to change normative behavioural beliefs that conflict with the principles of Positive Living. He raised the topic of sugar-daddy relationships (Ntsayagae et al., 2008), referring to chickens, which almost every family in Botswana owns. He asked people whether they had ever seen a rooster force itself upon a baby chick, anticipating their response: 'No'. He would then lay down a challenge: 'Why then should older men have sex with teenage girls?' (interview, 2010). These examples attest to Paul's creative ability to translate the scientific and rational promotional arguments of Positive Living into a narrative likely to resonate with target groups.

Paul also shared how he replaced risky behaviours with safer ones: 'I have decided not to have [penetrative] sex… because I fear re-infecting myself… The use of condoms is all

right… but I rather prefer… mutual masturbation [smiles] — I fancy that one!' (interview, 2006). He proposed that Botswanans revise their motive for sex 'to be faithful to each other, or we won't reach zero new HIV infections, as [is] our target' (e-mail, 2012).

Paul was a charming, compassionate and loving man. Backstage at the pageant, he kept the contestants calm by making them laugh, proclaiming that everyone needs their '15 minutes of fame'. A telling moment occurred when Paul mounted the pageant podium and answered the judges' question about how he would characterise a male role model in the fight against HIV. With a dazzling smile, Paul answered, 'A role model is a macho man — a charismatic macho man — smart, helpful, full of love, care and support'. Laughter and applause followed; he had clearly intrigued and charmed the audience.

The activities of the local and loving caregiver are difficult to enumerate. In the case of a stigmatised illness, face-to-face meetings with target persons require unique interpersonal skills and deep local knowledge (Liddell et al., 2005) in the translation, outreach and delivery of medical treatments and behavioural mandates. These activities create social, emotional and utilitarian value beyond those commonly studied in communities. Akman et al. (2018) highlight the 'value of effort', which creates positive feelings and community relationships for the entire community. The loving caregiver creates such values for others by bringing the afflicted dignity, love, hope and trust.

In sum, the findings reveal the idiosyncrasies emerging from communities and individuals' creativity in a universally unfamiliar situation. Abstracting the concept of hero and heroic actions risks missing the point that heroism comes in many forms, depending on individual talents and situational factors (Frisk, 2019).

Discussion – Everyday Heroes as Embodied, Embedded, and Educated

Mark and Pearson (2001) show how heroes can help to build a commercial brand. In contrast, our study provides insights on how everyday heroes strive to help others in a non-commercial setting — during a pandemic that is both unfamiliar and dangerous. Based on hero theory, we defined everyday heroes as ordinary individuals who engage in extraordinary efforts to help others despite calculated risk and who acquire and share expertise and ideas that challenge mainstream marketplace norms while still belonging to their community. We develop a typology consisting of four distinct types of everyday heroes, defined by their hero actions and the social arenas in which they work. Although everyday heroes follow similar journeys, they adopt a variety of actions uniquely drawing on their embodiment of the illness and embeddedness in the local context. In this section, we further unpack and theorise what enables everyday heroes in their attempts to save lives during a pandemic.

Embodied health refers to giving visible, tangible or corporeal form to an affliction (Oxford Dictionary). Research suggests that this gives greater potential for agency in the marketplace (Maguire et al., 2004). However, hero theory suggests that a hero must also embody a self-transformation journey that demonstrates hope to others (Burchardt, 2016). The hero self-transformation journeys in our study started with collective sharing and sense-making facilitated by the buddy programmes. This makes sense for several reasons, as pandemics are non-normative, and both health authorities and individuals lack established scripts for dealing with them. The collective resources of fellow afflicted peers provided the foundation to rebuild their lives, both health-wise and socially (Burchardt, 2016).

The self-transformation journeys suggest a dual embodiment of illness, involving both vulnerability to the illness and success in taking control of it. Here, vulnerability entailed feelings of fear, distress and disruption to social relationships, jobs and families. At the same

time, by appropriating the principles of the Positive Living Movement they could also act as community role models. Their effectiveness stemmed from a capacity to provide living proof that ordinary people can make the lifestyle changes needed to combat the disease. This is similar to how the breast cancer movement changed the public image of women with breast cancer from victims to brave survivors. Klawiter (2004) credits embodied health activists' work in community support groups and role-modelling of survival for much of this change. Moreover, when striving to influence powerful opponents (e.g. politicians, medical experts and public health officials), embodied tactics included assuming leadership roles within support groups and acting as lay experts on biomedical aspects of the disease (Zoller, 2005). On this note, our study suggests that cultivation of grass-roots support groups not only supplements authorities' communication but also inform and educate experts and authorities.

Our findings also offer an alternative perspective on a hero's journey as a collectively embedded endeavour rather than an individual one. The everyday heroes did not distance themselves from their peers, even when they returned to their communities as educated and trained spokespeople and change-makers (Frisk, 2019). Collective illness identities stem from consumers' consciousness of shared illness experiences with members of identifiable groups (Brown et al., 2004; Zoller, 2005). These identities typically form when people acknowledge common negative experiences of the illness and frustration and anger at a perceived lack of fairness in the health care system or a lack of access to necessary information. This is similar to how brand communities form and endure. The process entails consumers sharing experiences of heightened brand preference, consciousness-of-kind, common rituals and traditions and feelings of moral obligation towards community members (Muniz and O'Guinn, 2001). Collective illness identities can transform into collective politicised identities, reframing personal illness experiences into a broader social critique that views structural inequalities and social power structures as responsible for the causes and/or triggers

of disease (Brown et al., 2004). Politicised illness identities are based on a collective oppositional consciousness that 'binds members of a group against dominant ways of thinking by attributing problems and grievance to structural factors' (Brown et al., 2004: 60-62). Such identities emerge when an illness is widely recognised, if it can be linked to previous social movements, when the collective identity incorporates socio-political dimensions (e.g. gender, race or class) and if the illness affects a large number of people. The global success of the HIV/AIDS and Breast Cancer health activist movements can partly be attributed to the spillover from pre-existing politicised gender, racial and civil rights collective identities (Brown et al., 2004; Klawiter 2004).

Importantly, the education of the everyday heroes in this study is not top-down (see Castaneda et al., 2010). Rather, it evolves though multiple self-education experiences, co-creation and sense-making with other afflicted individuals in self-help and buddy groups. Further, it comes from formal training offered by NGOs, health authorities and the international health community. The most significant finding in this study is the heroes' bravery, courage and creative self-educational work, through which they find their own ways to translate medical knowledge into the local vernacular and practice (Robins, 2006). The acting skills of the local caregiver are crucial when using local codes to translate complicated scientific messages into everyday village life. The national role model used commercial communication and personal branding tactics so cleverly that she outperformed professional health personnel and politicians and charmed resistant village chiefs. Similarly, the national entrepreneur staged media-friendly events, such as the Mr. HIV/AIDS Positive beauty pageant. These were socially, administratively and economically complicated projects initiated to make changes and to create novel collaboration among stakeholders in the health ecosystem. The backyard gyms, created by the local entrepreneur, were venues of hope in a hopeless space. The diversity and type of everyday heroic actions go far beyond individual

hero journeys (Glazer and Glazer, 1999). Everyday heroes who assume leadership roles in illness communities adopt a tempered stance towards marketplace institutions and health care providers so they can stimulate rapid compliance with medical treatment to attempt to save lives.

An important limitation of our findings is tied to the limited sample size of 10 key informants. While all ten informants can be positioned within our typology, we have no guarantees that a larger sample would correspond equally well to the typology. However, we accommodated the limited sample by including supplementary sources of data such as on-site observations; in-depth analyses of archival data such as national and international public reports and health implementation programs; media coverage; follow-up interviews with some of the key informants, and public health servants. In addition, the ethnographic videotapes of the informant interviews and of the backstage and front-stage events became an almost inexhaustible source of information throughout the entire research process.

Opportunities for Marketing Research

Benefiting from rich and mature field data and our typology of everyday heroes, we present four unique takeaways from our study.

First, our typology of everyday people, who acquire a social position sufficient to convince (even resistant) others to change their behaviour, add to our understanding of existing concepts in marketing theory such as ‘early adopters’ (Rogers, 1995) affording others to observe the relative advantage of innovations, ‘market mavens’ (Feick & Price, 1987) sharing market expertise with others, and social media ‘leaders’ building cultural capital to influence large audiences (McQuarrie et al. 2013). Our typology offers marketing researchers a conceptual framework and operational definitions to study different ways ordinary people strive to empower themselves to effectively reach different target groups.

Second, the anti-vaccination movement during COVID–19 is a recent reminder that confidence in and experience with biomedical advice and treatment from authorities and experts varies both within and between countries. Likewise, during the global HIV/AIDS intervention in Africa some saw this as an act of recolonization and of blaming the disease on the African continent (Nguyen, 2009). Our typology unpacks the various actions everyday heroes engage in (sharing evidence and expertise, challenging marketplace norms, identifying with and building community). While the specific actions everyday heroes choose to challenge marketplace norms may differ across contexts, the dimensions and types of action in our typology may also apply to other contexts. Comparison of everyday heroism across sociocultural divides should be on the research agenda in the wake of the COVID-19 pandemic. In particular, we encourage marketing researchers to further explore the journeys of local heroes, who often work unnoticed by the media and political radars.

Third, our study suggests there is more to discover on how everyday heroes develop and enact innovative and sophisticated communication tactics. Field studies from the early HIV/AIDS health movement (Wohlfeiler, 1998) and the breast cancer movement (Klawiter, 2004), showed how afflicted people formed alliances with civil rights movements to frame the disease discourse as a civil rights issue in opposition to mainstream stigmatizing rhetoric. We find that the everyday heroes developed unique rhetoric tactics for different situations by simultaneously challenging and educating their peers and opponents. Hence, the everyday heroes had the ability to mould imports from social movements' tactics into their own communication strategies. How they do this deserves further exploration.

Finally, our study demonstrates that it takes a village of heroes rather than one elevated 'hero-for-all' to help others and to elevate embodied and embedded experiences into politicized collective agendas. The specific methodological approach adopted in this study — videography based on ethnographic field study — provided a unique opportunity for

Botswanan government representatives, NGOs and, most importantly, the everyday heroes, to share (the videography - WALK THE TALK: Living Positive With HIV - is available at Vimeo.com).

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Notes

ABBREVIATIONS:

AIDS	Acquired Immuno-Deficiency Syndrome
ART/ARV	Anti-Retroviral Treatment
BONEPWA	*Botswana* Network of People Living With HIV/AIDS
COCEPWA	Coping Centre for People Living With HIV/AIDS
HIV	Human Immunodeficiency Virus
HIV+	Human Immunodeficiency Virus-positive
NGO	Non-Government Organisations
PLWHA	People Living With HIV/AIDS

POSITIVE LIVING LIFESTYLE

- Prevent the spread of HIV.
- Be informed about your health.
- Take medications prescribed by health care workers.
- Work as your energy allows.
- Avoid stress.
- Maintain good nutrition.
- Prevent infections.
- Get regular exercise.
- Seek regular medical care.

UNAIDS United Nations HIV/AIDS Programme

The ethnographic data consist of transcribed interviews, videography and e-mail correspondence with informants. These data archives are stored in files with the first author: ingeborg.kleppe@nhh.no.

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Table 1. Informant Details (all names are pseudonyms)

Informant Demographic Details	Year of diagnosis/ going public nationally	Hero action arenas
Amogelang Female, 29, single Unemployed aspiring politician	2003 – Early presenter with no illness apparent 2005 – One of 20 people to go public	Runner-up in the 2005 Miss HIV Stigma Free. Local support group member
Andrew Male, 30, de facto relationship with 3 children Unemployed, former building contractor	2004 – Late presenter, very sick at diagnosis 2006 – Went public	Contestant in the 2006 Mr. HIV/AIDS Positive Living. Local support group member
Donald Male, 56, married twice, three children and two grandchildren Director national PLWHA network, former truck driver and farmer	1993 – Late presenter, very sick at diagnosis 1993 – First person in Botswana to go public	Founder and Director BONEPWA (4,000 members)
Joseph Male, 37, married with 2 children, younger child HIV+ Commercial artist, former soldier	2004 – Early presenter with no illness apparent 2006 – Went public	Contestant in the 2006 Mr. HIV/AIDS Positive Living. Local support group member
Otsile Male, 27, single, lives with parents, at least one child Un-employed, leader of a crime gang	2004 – Early presenter with no illness apparent 2006 – Went public	Contestant in the 2006 Mr. HIV/AIDS Positive Living. Support group leader and buddy
Paul Male, 40, single, six children Unemployed, former police officer	2004 – Late presenter, very sick at diagnosis 2006 – Went public	Contestant in the 2006 Mr. HIV/AIDS Positive Living. Local support group member, home-care volunteer and buddy
Precious Female, 37, single Part-time receptionist (former legal secretary)	2000 – Late presenter, very sick at diagnosis 2005 – One of 20 to go public	Winner 2005 Miss HIV Stigma Free. Advocate, counsellor, volunteer and buddy
Robert Male, 37, has a girlfriend Unemployed. Former paid HIV counsellor at a hospital, insurance consultant/driving school instructor	2002 – Late presenter, very sick at diagnosis 2006 – Went public	Runner-up in the 2006 Mr. Positive Living. Local support group member
Tau Male, 29, has a pregnant girlfriend Unemployed	2002 – Late presenter, very sick at diagnosis 2006 – Went public	Winner of the 2006 Mr. Positive Living. Local support group member
Thomas Male, 35, single Receptionist at Barclays Bank	2008 – Not HIV+ so went public nationally with the adoption of the Positive Living lifestyle	Winner of the 2008 Mr. Positive Living Local support group member

Lay Experts	
Ruth	Volunteer community organiser, local rural youth community organisation
Morapedi	Pastor, Pentecostal Holiness Church
Bolokang	Program assistant, National HIV/AIDS Coordinating Body
Brian	Project manager, National People Living with HIV/AIDS Support Group
Kagiso	Master's student in public health in a Western country
Itumeleng	Consultant to the Ministry of Health
Kefilwe	Officer, National Office of Gender Affairs

Table 2. Archive Data Sources

Documents and reports	- Botswana HIV/AIDS public health intervention campaign from 2000–2007. - Public sector institutions, e.g. the Botswana government, especially the Ministry of Health and the National AIDS Coordinating Agency. - State-owned media companies, e.g. *Daily News Botswana*, Radio Botswana and Botswana TV. - Other government-linked institutions (albeit at arm's length), including local NGOs, often with international links, that foster supportive communities such as BONEPWA, the Centre for Youth and Hope and the Coping Centre for People Living with HIV/AIDS.
Publicly available data	Public health programme implementation, market responses and progress reports available online, including from the National AIDS Coordinating Agency, the United Nations Programme on HIV/AIDS, AVERTing HIV and AIDS and the US Agency for International Development.
Existing research	Academic articles and research reports on the context (see references).
Mass media, popular culture	Video-ethnographies, newspapers, televised reports of beauty pageants, popular and fictional literature documenting gender roles and cultural and religious norms and practices.

Table 3. A typology of everyday heroes – Self-transformation journeys and hero actions

	Hero actions	
	Changing social norms	Building new institutions
Target arenas National and international stakeholder Arenas	Self-transformation journey *National Role Model: Precious* From black sheep in the family to Miss Stigma Free – 'Beauty with a purpose'. Hero actions 1. *Sharing evidence and expertise* Promoting and enacting Positive Living as a (personal) brand. 2. *Challenge marketplace norms* Changing marketplace discourses of the illness and the afflicted. 3. *Identify with and build community* Persuading power elites to publicly adopt and advocate antiretroviral treatment.	Self-transformation journey *National Entrepreneur: Donald* From lorry driver to institutional entrepreneur and national watchdog. Hero actions 1. *Sharing evidence and expertise* Advocating and monitoring the public health policy agenda. 2. *Challenge marketplace norms* Assembling resources and bridging actors in the health ecosystem. 3. *Identify with and build community* Building a national support network for PLWHA.
Grassroots and community arenas	Self-transformation journey *Local Caregiver: Paul* From carefree charmer to outreach caregiver. Hero actions 1. *Sharing evidence and expertise* Caring for the HIV diagnosed and their significant others at outreach sites. 2. *Challenge marketplace norms* Disarming local taboos and harmful health practices. 3. *Identify with and build community* Translating the illness treatment into local everyday life routines.	Self-transformation journey *Local Entrepreneur: Otsile* From petty crime gang leader to community health entrepreneur and leader. Hero actions 1. *Sharing evidence and expertise* Displaying personal adoption practices in everyday community life. 2. *Challenge marketplace norms* Creating new community activity arenas to replace risky behaviour. 3. *Identify with and build community* Orchestrating social events to integrate the afflicted with others.

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Marylouise Caldwell (1956-2021) was an associate professor at the University of Sydney. In her research she sought to examine solutions to substantial social issues, which reflects in her pioneering and award winning videographies *A Right to Life: Reducing Maternal Death and Morbidity in Pakistan* and *Walk the Talk: Living Positive with HIV* from Botswana. Her work has been published in e.g. Consumption, Markets & Culture, European Journal of Marketing, Psychology & Marketing, and Marketing Theory.

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