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Reflecting on health and illness through the lens of the HIV epidemic in Uganda

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Abstract

This chapter will focus on how the knowledge and experience of living through the HIV epidemic shapes older people's responses (and fears) about chronic illness and health emergencies such as the COVID-19 pandemic. Using the example of Uganda, we examine the ways in which the particular time people first heard about HIV, or encountered it in their lives as a result of their own HIV diagnosis or a diagnosis within their family or wider community, affects their understanding and perception of ill health and the concerns about the risks HIV continues to pose. We describe how the response to information about an asymptomatic chronic condition (at an early stage of potential disease), or a new illness like COVID-19, may be shaped by the experience of living with HIV or taking care of someone with HIV-related illness in the past. Such experiences shape older people's understanding of symptoms and expectations of the time-line for the illness development.

Majse Lind and colleagues (2021), described the resilience of older people in the United States managing with the COVID-19 pandemic, in the following way:

> `Older adults have the strength of experience. They have seen the world fall apart and come back together again. They have dealt before with months or years of anxiety about invisible threats, frustration at restrictions on activities, financial insecurity, isolation, and the illness of love ones. Specific memories of how they handled these times can guide their behavior now.'

These words could apply to older people in many other contexts; what someone has lived through provides memories which influence how present and future challenges, including health challenges, are faced (Mohatt et al., 2014). A person in their seventies in rural southern Uganda will remember the political turmoil of the 1970s and 1980s, when violence and destruction threatened lives and livelihoods. That turmoil was followed in the decade thereafter by the HIV epidemic, which cut short the lives of many loved ones, some of whom they nursed in the final weeks of their lives. Those memories continue to guide them, to serve as examples of how to manage loss and shortage and how to cope with future ill health and fading strength. That `strength of experience' has served as a template for managing the threats posed by COVID-19; a cruel pandemic that poses a particular threat to older adults in Uganda as they age, just as HIV-infection had cast a shadow over the freedoms of their younger selves.

Memories, and often rehearsed stories of past times, are an important part of managing the passing of time in the daily lives of many people, particularly as they age. Barbara Adam (1994) cites Stegmüller (1969, p. 175) to explain the importance of such repetition: it is not `a mere binding of the present to that which has irrevocably gone, but a deep response to that which has been'. Yet, such repetition also serves as a way to try and revoke the shadow, the palimpsest, the traces of the past found in the present.

Memory is not only cognitive but also biological. On an individual level, our body has a memory of past illness. Experience of sickness in our childhood affects how we respond to later infections; measles or mumps as a child can confer immunity in adulthood; a memory `forced' by infection or by vaccination. Our body remembers the infection and resists a return of that illness. Equally, if we learn that taking a certain over the counter drug, or using a particular herb, can aid our recovery from a cold or from influenza, we will remember to use that remedy when that sickness, or something that seems like it, comes again. Leventhal and colleagues (2016) draw on this experience for the `Common-Sense Model of Self-Regulation' to describe how individuals use their previous experiences of ill-health to inform their management of new health challenges, even if they are not exactly the same. When faced with the diagnosis of diabetes or raised blood pressure, a person may doubt the severity of the condition because there is no tell-tale high fever or similar symptom which has signalled a serious illness in the past, such as malaria. Equally the response to being given information by a nurse about a serious chronic condition (for example, an early stage of kidney dysfunction which may be almost asymptomatic), may be shaped by the experience of people's knowledge of other conditions such as HIV, which has an asymptomatic phase. Assumptions are made about the likely course of the disease as the person looks out for tell-tale symptoms and, despite what they may be told at the clinic, questions the diagnosis when the symptoms they anticipate fail to materialise. Even for a new infection or sickness, such as AIDS in the 1980s or COVID-19 in 2020, what people hold beliefs about, and have expectations of, may draw more on their own memory of previous sickness and the beliefs held by people around them, than on messaging from health providers. Those health professionals are also learning about the new condition. The treatment strategy of the person with the infection is informed by their understanding of the course of other infections, which may mirror the new illness as they gather new knowledge. .

In this chapter we reflect on the timeprint of an epidemic, to adapt a concept developed by Barbara Adam (2008): how far the impact of past epidemics is reflected across time to the management of present (and future) health crises. We look at the ways in which the knowledge of the HIV epidemic, at a particular time and at different times and places, shapes the understanding and actions of older people in the present and future when managing sickness and new threats posed by disease.

Methods

We draw on the findings of three studies in this chapter, all conducted in a rural sub-county in Kalungu District, which borders Lake Victoria in southern Uganda, where the Medical Research Council/Uganda Virus Research Institute Programme of AIDS established a research base in 1988/1989 (Mulder, 1996).

The setting

Most livelihoods in the area are based on small-scale farming, with families producing food for themselves and small amounts of cash crops such as bananas and coffee. Most homesteads have less than five acres of land. There are only a few sizeable landowners and relatively few householders who are landless. Trading (in food items and clothing), brick making, vehicle and bicycle repair, running shops and bars as well as hair and beauty salons provide additional livelihood options. In addition, some family members move away for work in the nearby fishing sites on Lake Victoria or in Masaka (a nearby town) or Kampala, the capital city. Most of the population is ethnically Baganda (75 per cent), but there is a large representation of immigrants from Rwanda (15 per cent) and a smaller number (four per cent) from Tanzania. People from other Ugandan ethnic groups make up the remainder. The main local language is Luganda which is spoken and understood by all the ethnic groups in the area. The community is predominantly Roman Catholic (58 per cent), but 28 per cent of the population is Muslim, and 12 per cent Protestant. Just over 50 per cent of the population is under the age of 15 years. Nahemow (1979, p. 172) describes the Baganda, one of the dominant ethnic groups resident in central and southern Uganda, as having a ‘loose patrilineal structure’. All children belong to their father’s clan (Roscoe, 1965, p. 128). However, the system of descent does not mean that a father and his children, once they have grown up, stay together. Households are often nuclear with kin often living far apart and the wives of a man who practices polygyny may each have a separate household, with the husband circulating amongst the homes. Under the present laws of Uganda legal polygamy can only exist if a man marries under customary or Islamic law, but some men in legally monogamous unions go on to `marry’ additional wives. The most recent census (Uganda Bureau of Statistics, 2014) records eight percent of women being married or cohabiting in a polygamous relationship; the number in informal polygamous unions is likely to be higher than this (Seeley, 2012).

Except for the main highway, which cuts through the District from north to south, there are no tarmac roads in the area and the mud roads connecting the villages, as well as the main road to Masaka, are often muddy and slippery when it rains or deeply rutted when it is dry, making travel, particularly for older people, difficult.

The population of Kalungu district was just over 350,000 at the time of the last national census in 2014. About 5 per cent of the total population is over 60 years old (Uganda Bureau of Statistics, 2014).

Research in the Medical Research Council/Uganda Virus Research Institute and London School of Hygiene and Tropical Medicine (MRC/UVRI and LSHTM)[1] cohort, which cover 25 villages in Kalungu District (Asiki et al., 2013), found HIV prevalence in the adult population (age 13+) to be 8.5 per cent in 1990/1991, 7.0 per cent in 1998/1999, 8 per cent in 2004/2005, approximately 9 per cent in 2017 and 10 per cent in 2019. Anti-retroviral therapy (ART), which enables people living with HIV (who adhere to ART) to suppress the virus and live a healthy life into old age, was introduced into the area in 2004.

Study methods

The first study we draw from is the `Trajectories study' (Seeley, 2014; Seeley et al., 1995). In 1991/1992 the members of 27 households took part in a year-long ethnographic study of the impact of HIV on people's lives and livelihoods. The households were chosen purposively from the census list compiled in 1990 to represent a cross-section of different household types (by sex and age of household head, as well as socio-economic status). A team of nine local people (four women

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[1] The MRC/UVRI Uganda Research Unit on AIDS joined with the London School of Hygiene and Tropical Medicine in 2018, to become the MRC/UVRI and LSHTM Uganda Research Unit. `AIDS' was dropped from the name to reflect the broadening of the health research of the Unit,

and five men) trained in ethnographic research, paid monthly visits to the study households assigned to them for the year to record changes in different aspects of the household, such as composition, employment, health, food consumption and social networks. Detailed notes were written up immediately after the visit. Monthly meetings were held so that the team could discuss emerging themes and agree on any additional topics to focus on in their visits relevant to the season or current events. In 2006/2007 the study was repeated, collecting the same detailed information on day-to-day life, and also changes in socio-economic status and household members' memories of what had happened in the intervening 15 years. This time the research team was made up of two women and three men, who visited the households, each going to their own assigned households once a month. Members of 24 of the 27 original households participated in the restudy. Life histories of all adult members were collected. Eleven of the household heads were the same in 2006 as in 1991, they and some members from other homes were aged over 60 years in 2006; it is these people we draw information from for this chapter.

The second study, which took place in 2013, was the Research on Ageing and HIV (ROAH) study. We conducted 11 individual in-depth interviews by an experienced female interviewer. This time interviews were tape recorded, with the participant's agreement. An interview checklist was used consisting of broad topics such as `care giving' or `visits' to serve as a memory aid for the interviewer. All interviews were, however, conducted in the style of an informal conversation. The interviewer transcribed and translated the taped interviews.

The analysis of the data for both of these projects was done manually by the interviewers and lead social scientists using thematic content analysis. The information in scripts/transcripts was coded on a range of themes agreed in advance by the team for each study, and thematic summaries written up on each theme. We ensured that differences and disagreements over coding were resolved through discussion, with constant comparison used throughout the process to avoid shifts in code use over time.

The third study is a COVID-19 survey in 25 cohort villages in 2020 and 2021 where we are collecting quantitiative data on the experience of the pandemic, both in terms of infection, but also knowledge and attitudes towards infection. We draw on some of the broad free text statements older participants made in the course of the ongoing data collection.

All three studies have overall approval from the Ugandan National Council for Science and Technology. Ethical approval was given by the review board of the Uganda Virus Research Institute. All participants provided written informed consent for the use of their anonymised data in publications. All the names used in this chapter are, therefore, pseudonyms.

In her essay on the cultural anthropology of time, Nancy Munn (1992) describes a metaphor from the work of Christine and Stephen Hugh-Jones in Northwest Amazonia (Hugh-Jones, 1977), where the Barasana people describe their generations growing away from their ancestors, like leaves piling up on the forest floor. Performing male initiation rituals, is described as `squashing the pile' because the repetition reconnects the new initiates with their ancestors and all those who have performed the ritual in the past. In a way, we can think of the memories of the older people we spoke to as layered; when new health challenges arise the layers squash to draw from past practice and the things that provided comfort. It is to those memories we now turn.

Memories of loss

A few years before her death in 2012, Sara who was then in her early 80s, recalled a time when the home she now shared with her co-wife Lydia was full of their offspring and bustling with visitors. They were a well-off family, with plenty of land and resources, enough to ensure all the children were educated. She sighed and reflected on the past 20 years, the two decades since their husband died in 1992. `All our children are finished' she said. Of Sara's eight children, only two were still alive in 2012, while Lydia, who had given birth to 11 children had only three still alive at that time. All had died of AIDS-related illnesses; all were buried in the family burial plot close to their main house (Seeley et al., 2009).

There was a new, unfinished house which stood close by to their main house. Sometimes a niece slept there with Lydia to ensure the place remained in use and was secure. Lydia commented:

> "Our son who was our right hand put up this [the new structure] house so that he could care for us when near us, but he died, and it was his dead body that entered here. His grave is also over there where his father's [grave] is."

Eunice, their neighbour, recalled a time when she and her family would become tense when they heard a vehicle at night on the dirt track which ran between her home and the plot where Lydia and Sara stayed, assuming another dead or dying person was being taken to her neighbours' home for burial or for care in their final days. Eunice commented that in the 1990s HIV `almost killed the whole village!'. Eunice' own husband and son had died because of HIV and she was living with HIV herself and taking anti-retroviral drugs.

For Sara, Lydia and Eunice, the threat posed by HIV-infection was a shadow over their lives, a threat that had resulted in death. The place they lived, about 100 kilometres north of the Tanzanian border, had once been the epi-centre of the HIV epidemic in Africa (Barnett & Blaikie, 1992). That epidemic was the reason the research organisation we work for was based there: in 1988 an agreement between the Ugandan and British Governments led to the establishment of the then Medical Research Council and Uganda Virus Research Institute Research Programme on AIDS. The purpose of the programme was to study the HIV epidemic – to increase the understanding of an infection that had taken hold in that area, since the first documented cases in 1982 (Mulder, 1996; Serwadda et al., 1985). Mixed in with the growing body of knowledge of an infection which attacked the immune system so violently it resulted in death, were the accounts of people struggling with grief. Increasingly families witnessed the loss of the young people they had invested resources in to be educated to secure the family's future and care for the older people in their final years.

Memories and history to guide the present

Howard Phillips (2020) reflects on the value of history in understanding the COVID-19 pandemic, which has swept the globe in 2020 and 2021:

> `it is necessary to recognise that history, or more precisely, our knowledge (such as it is) of the past is closely tied to the present too. Not only does it

> explain how the present has been reached – every current problem has its source in the past – but it is also able to offer comparative historical examples, helping us to keep the present in perspective'.

He reminds us that South Africa (where he lives) has experienced many pandemics: smallpox (18th and 19th centuries), bubonic plague (1901-1907), `Spanish' flu (1918-1919), polio (1944-1963) and HIV (1982-continuing). In a 2004 publication on the history of HIV in South Africa, Phillips takes to task those who had claimed that there was `no parallel' in history for the HIV epidemic and quotes from a paper presented at a conference in Johannesburg on `AIDS in Context' where the speaker, Coovadia (2001), said HIV was an epidemic `the likes of which we have never seen before'; language which resonates with the frequent claims that COVID-19 is `unprecedented'. The global response with widespread lockdowns and other containment measures may be unprecedented (Yan, 2020); but the COVID-19 pandemic, and indeed the HIV epidemic, is not; a point we return to at the end of this chapter.

In Uganda, as in South Africa, the HIV epidemic followed other disease trajectories. In the nineteenth century outbreaks of plague and smallpox as well as endemic malaria affected the area, the Buganda Kingdom, where Sara, Lydia and Eunice lived at the time of our research. In 1905, sleeping sickness in Buganda and neighbouring Busoga killed about 250,000 people and resulted in the then British colonial government moving people away from the shores of Lake Victoria to re-settle 24 kilometres in land. The evacuation caused widespread disruption, but it did help to reduce the number of deaths (Berrang-Ford et al., 2006; Seeley, 2014). Syphilis dominated the discourse on the health of the population up to the 1930s, with debate as to whether the disease seen was endemic syphilis, venereal syphilis, yaws or tropical ulcer (Lyons, 1994). Davies (1956) believed that endemic syphilis was an old disease in Buganda, spread non-sexually, which most of the population had had, and which conferred some immunity to venereal syphilis. Meanwhile, migrant labour from neighbouring countries (particularly Rwanda and Burundi) was affected by `the imposition of strict quarantine measures in Ruanda-Urundi on account of outbreaks of typhus, smallpox and cerebro-spinal [sic] meningitis' (Powesland, 1954, p. 39). These distant epidemics are long forgotten by the majority of contemporary Ugandans, just as the Spanish flu pandemic in the early twentieth century was, until recently, barely remembered in many parts of the world. Indeed the outbreaks in 1918 have been called `a "forgotten pandemic," lost in the archives, amidst records of the Great War, the armistice, and the new era of modernity ushered in by these cataclysmic events' (Hovanec, 2011, p. 161). Some commentators (such as Bristow, 2010; Bristow, 2012) suggest that the ways in which this epidemic was `forgotten' are bound up with the war (the First World War) which had just ended; people wanted to get on with their lives.

People the age of Lydia, Sara and Eunice, all in their 80s, certainly knew of outbreaks of disease in the past, and famine and crop failure, but they had also all lived through long periods of political instability. Prior to 1986 President Yoweri Museveni came to power following a prolonged bush war which ousted President Milton Obote and before that, in 1979, Tanzanian troops crossed the border to support Obote in the liberation war against Idi Amin. When we first met them in 1990 the stories of their experience of the wars were fresh in their memories and they, and others, recalled hearing fighting near their homes in 1979 and of hiding from soldiers. By 2006, when older people talked about the past, those stories of war, even if not forgotten, were over-shadowed, covered in a layer if you will, by tragic accounts of children and grandchildren lost to HIV and, for Lydia and Sara, the management of their own ill health (Lydia had a breast removed because of cancer, she also suffered from diabetes, and Sara had broken her hip in a fall). The HIV epidemic was seen through the lens of the care provided for their ailing children, who could not at that time be saved from an early death, and their doubts about the new drugs (ART) that might keep their grandchildren living with HIV alive.

As the `common-sense model' developed by Leventhal et al. (2016) suggests, people draw on past-experience to manage health challenges, but the memories of managing other challenges in their lives also guide coping measures. DeLongis and Morstead (2019) point to the importance of the social context in understanding the `common-sense' that a person draws on when confronting illness; the knowledge of an older female relative may be heeded more readily than that of a young female nurse in a public health clinic. Likewise, religious teachings, and beliefs in divine support, may provide comfort when the outcome of a diagnosis hangs in the balance. Sara, for example, recalled how she used to cope with news of her husband's other wives (he had children by at least five women) by saying the Rosary to calm herself and give her strength. She said that she used that same ritual of prayer, and the memory of the support she had felt from that action, to cope with the strain of nursing her own children, and some of her husband's other children who came to stay at their house. Her faith gave her strength through the terminal stages of their AIDS-related illness.

The layering of experience and new knowledge

The experience of illness in past times, or actions taken to comfort in times of stress, may conflict with treatment for a new sickness, and adversely affect treatment outcomes. We encountered this in our own work on chronic kidney disease (Seeley et al., 2020), where people in the early stages of kidney dysfunction expressed disbelief that their condition was serious or indeed life threatening because they were only prescribed a short course of treatment (often for a urinary tract infection for those in the early stages of kidney dysfunction), which contrasted with other serious illnesses, such as HIV-infection, which require life-long treatment. Yet the dramatic transformation in the management of HIV, the changing of guidelines as new treatments have evolved, presents a challenge to the experience gained by older people as they support their loved ones in often difficult and painful last illnesses as they died. For some, the confidence that new treatments have transformed a fatal illness to a manageable chronic condition is met with incredulity, if not disbelief, and perhaps suspicion. The clash of the different experiences of the HIV epidemic was illustrated in the illness history of Mary, who we met in 2013.

Mary was 67 years old when we met her, living with HIV. She had been on antiretroviral therapy for about seven years at that time. As she told her illness story, she recalled the episodes of sickness that had prompted her to seek a test for HIV, following the death of her husband (in about 2003). She said that she had lost a lot of weight and `could no longer see properly'. She recognised the signs and was not surprised when she learnt of her infection.

Her feelings of stigma about her condition meant that she had only told one daughter about her infection, and only told her when she was staying with her, because the daughter saw her taking her tablets. She was wary of people mocking her for being an older woman living with HIV. She said people would criticise her for becoming infected with what was considered a young person's illness. She knew people did not know that her husband died of AIDS-related illnesses because the family had kept that a secret. Many families chose not to disclose the cause of death because of the stigma and fear which still surrounds the condition. Mary told us that when she learnt of her condition she avoided going to social events where people might gossip about her, and would whisper, she feared, that she has slept with many men (like a young woman). Mary said that she took care to follow the instructions given to her by the doctors:

> `feeding myself, doing less work as well as getting enough rest. They told me to eat greens, jack fruits, and paw-paw; they told me to eat all those things that build up the body.'

She went on to say that her children helped her with food when she could not get enough from her garden. The daughter who knew about her infection paid particular attention to checking that she had good food. Mary's memory of how ill she had been before she began the antiretroviral drugs, haunted her:

> `I was very sick and nearing death; having become swollen and they even gave me supplements so that I get more blood. Was I not nearly dying and following my husband? All these legs had swollen and a person who used to have clear skin on my feet, the feet now turned dark!'

She had watched her husband suffer and die from the symptoms she had suffered from; he died before the new drugs had come to the clinic. Yet, Mary saw her drugs as providing a temporary pause before the serious sickness returned. Even though Mary was adhering to her antiretroviral drugs she considered that she was going to die soon. She commented that she would now die before her remaining children. However, in addition to anticipating her own death she was fearful of losing her children, as so many neighbours had done. She explained:

> `…if they happen to die before me, who can be there to care for me? It is very bad for the young ones (children) to go and we the oldies to remain! It is worrying to lose someone who would have cared for you and that is the one you bury! That upsets us very much and personally I pray it does not happen that way.'

Mary had received her diagnosis just as the antiretroviral drugs came into use in the clinic. While the drugs had restored her health, they had not taken away her memories and fear of what HIV can do to a body, her body. The drugs could not take away her certainty that she was just about to die.

Eunice, who had nursed children in her household until death recalled the suffering in the early days of the epidemic when no one knew how to treat those who were so ill. She recalled vividly the sickness people suffered from. She said that people in the past used to have wounds all over the body, their hair would fall out, they would have severe diarrhoea and, to make matters worse she said it was believed that it used to `chop off men's private parts and for the women it could make holes in their private parts'. Eunice recalled the first time that they heard of the new drugs and marvelled at the people who she had seen get so thin and who had been ready to die, who had got better when they had accessed that treatment. Yet, she worried about a time when the drugs would stop working, she like Mary, could not believe that these new drugs could keep working against such a powerful condition. She was convinced that when the drugs failed HIV would once more `finish the young people off'. Eunice knew that HIV was still something to be concerned about and these worries about the future of their children `raised parents' blood pressure', Eunice said.

Managing COVID-19 by drawing on the memories of HIV

Sara, Lydia, Eunice and Mary all complained that young people no longer took HIV seriously; the children had not seen the pain HIV could bring. Adolescents and people in their early twenties had no memory of the suffering the infection caused because they were small children or not yet born when ART became available. The messages on HIV were the familiar backdrop to their lives on the radio, television and on posters; a litany to which many paid no heed.

The particular calendar time a person encounters HIV and the stage they reached in their life-course, affects their understanding of the infection and their perception of the nature of the ill health the virus could cause. The social and historical context of a person's life therefore shapes their concerns about the risks HIV might pose.

With this in mind, it is perhaps not surprising that when a national lock down was imposed in March 2020 in Uganda to prevent the spread of the new SARS-CoV2, which causes COVID-19, many people – particularly older people -- were very fearful. Older people expressed the view that the infection must be much worse than

HIV, if the Government told everyone to stay at home. Such a measure had never been put in place for HIV or Ebola. Older people were worried for their children and grandchildren who work and stay in towns, because they were being told at the time of lockdown that COVID-19 was mostly infecting people who stayed in big towns, and those who travelled a lot, particularly those who were travelling outside Uganda. Remembering HIV, which had affected so many younger people, the threat of COVID-19 caused many who had travelled to go home, to the rural areas, urged to do so by parents and grandparents. Yet, while these younger people seemed to be a risk group for carrying the virus, the messages about `risk groups' for severe COVID-19 caused consternation; these groups were older people, and people with diabetes and hypertension. Some older people were very worried by these messages because they thought that getting COVID-19 would lead to their death since most of them are already living with comorbidities, particularly hypertension, or are frail because of age. A report compiled by the Partnership for Evidence-Based Response to COVID-19 on the state of knowledge of COVID-19 in different countries around the world, noted that:

> `Nearly three-quarters of respondents in Uganda said that they thought COVID-19 would affect very many people in the country. […] more than 60% of survey respondents in Uganda said that they believed COVID-19 would seriously affect their health if they were infected. […] Belief that the virus would seriously affect their health was highest among older respondents (> age 45).' (PERC, 2020)

Meanwhile, the Government officials were quietly confident that the country could manage the threat. Measures in place to counter other infectious diseases were repurposed to address COVID-19. The speed in which the lockdown came in and the borders were closed, led many to believe that SARS-Cov-2 would be kept out.

> `When much of the world was waking up to the enormous implications of a global pandemic [COVID-19], Uganda was already a step ahead thanks to Ebola…'

So begins an article of the WHO-Africa website in September 2020 (WHO Africa, 2020). Melissa Parker and colleagues (2020), note that in the west and north of Uganda where recent Ebola outbreaks were vivid memories and concerns about Ebola coming back over the border with the Democratic Republic of Congo, widely discussed, there was `a willingness on the part of Ugandans, whose livelihoods are not threatened, to respond seriously to the threat of COVID-19' (page 667). A sharp contrast to so much of Europe and North America where early on, COVID-19 was dismissed as little more than a cold, and there were widely held beliefs, which persist, that the seriousness of the pandemic was overblown and the news of the pandemic was a hoax (van der Linden et al., 2020). In places where life threatening illness is rare, and pandemics happen to other people, or in other parts of the world, a common-sense model would suggest that COVID-19 might result in a few days in bed at worst, like a bout of influenza, and then the sickness would pass. Older Ugandans draw on other `common sense' and arrive at a different conclusion.

It is hardly surprising that parallels are drawn between conditions such as HIV and COVID-19 in Uganda. Beliefs that once a person is infected with SARS-Cov-2, infection will lurk in the body forever and a person will continue to be a threat to others make sense against the backdrop of HIV. Masks and physical distancing, signs of contagion, amplify the threat, as does misinformation on social media.

Families where members have had COVID-19 are experiencing stigma and prejudice.

The long period of time over which HIV can unfold in an individual's life, in a family and in different societies, is firmly embedded in the memories of older people in Uganda. These memories contain the rumours and uncertainties which have evolved over time and combine with new, factually correct, prevention messages, to create a shifting backdrop which colours the understanding not only of HIV, but also of new threats like infection from SARS-Cov-2 and the resulting illness COVID-19.

A palimpsest of epidemic responses

A temporal appreciation of these changes allows us to comprehend the timescape of an epidemic for someone like Eunice, or Sara and Lydia, or Mary. They all knew a world before HIV, they all nursed children who suffered and died, they knew of new drugs which allowed people like Mary to regain her health. But this timescape is not a neat progression; memory and knowledge from one time period mix with others, to tinge hope with despair. The experience of these women is very different from a 15-year-old born in 2005, born into a world in which the HIV epidemic seems manageable, and the COVID-19 pandemic is something that happens to people in other countries.

Carol Kidron (2009) describes the `lived presence of the past' in her ethnography of Holocaust trauma survivors and their descendants in Israel. She describes how she began to understand that even though the past was not spoken about by survivors, their descendants felt `the silent presence of the Holocaust in the everyday life of the survivor home' (p. 6) through the behaviour of their parents or a chance remark. So it is in many families which have been scarred by deaths in the past because of conflict and HIV. And even if stories are told, not only may children and young people quickly tire of older people reminiscing about the past, but perhaps because of the nature of the epidemic, and the shame attached to the infection, it is something many would prefer not to talk about at all. This is one of the `timeprints' of the epidemic. The immorality and fear attached to HIV taints the present and soils new contagious conditions like COVID-19 into the future.

Conclusion

As Roth (2020, p. 15) observes, the de-emergence of a pandemic, unlike it emergence and spread, can be hard to place in time. The end of a pandemic is surrounded by uncertainty as some rush to forget and get on with their lives, and others remain fearful and watchful; conscious of a lurking threat. Understanding the lens through which both infectious and non-communicable disease are viewed by different people, particularly older people who may draw on many years of experience to manage sickness, is essential for future prevention and support. Understanding not only the temporalities of disease and treatment progression but also the context in which disease emerges and is managed, is essential for public health messaging and epidemic response. Documenting the `making sense' of disease and misfortune which goes on in people's homes and families, as well as on social media, is an important contribution to the management of present and future outbreaks. Our on-going findings, and those of others, contribute to a dialogue about the need to work with people in different places, to tailor global responses and co-produce the messaging (Turk et al., 2021).

The Spanish influenza outbreak may have killed many millions of people around the world, but it lasted for two years and then for many it was over; people wanted to forget. The same may be true for COVID-19, or perhaps COVID-19 becomes a seasonal illness managed with an annual vaccination. The same is not true for HIV, even though it can be managed with ART, a cure is not yet assured and many people continue to suffer with AIDS-related illness and death because they are diagnosed too late or not at all. The concerns expressed by the older people in the area in which we work in Uganda, who remained watchful, serve as a reminder of the lasting emotional pain pandemics can and do cause.

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