

RESEARCH ARTICLE

Adapting to change during the pandemic: The impact of COVID-19 on people living with HIV, and their coping strategies

Tam Chipawe Cane

School of Education and Social Work, Department of Social Work and Social Care, University of Sussex, Brighton, UK



Correspondence to: Tam Chipawe Cane, School of Education and Social Work, Department of Social Work and Social Care, University of Sussex, Brighton, UK; E-mail: Tam.Cane@sussex.ac.uk

Received: February 25, 2023;

Accepted: August 2, 2023;

Published: August 14, 2023.

Citation: Cane TC. Adapting to change during the pandemic: The impact of COVID-19 on people living with HIV, and their coping strategies. *Soc Work Soc Welf*, 2023, 5(1): 263-270.
<https://doi.org/10.25082/SWSW.2023.01.001>

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Abstract: Background: COVID-19 lockdowns led to people living with HIV experiencing lack of social connectedness, social isolation, difficulties with using technology and accessing health care and support services easily. The presented study sought to understand the challenges caused by COVID-19 and coping strategies. Methods: The study was conducted using focus groups with nineteen participants. Participants lost social connectedness, struggled to learn technology, and felt isolated in the absence of face to face peer support activities provided by HIV community support services. Participants employed a range of positive coping strategies including appreciation of the outdoors and volunteering. Conclusion: People living with value social contact and face-face support offered through HIV voluntary sector organisations. The absence of this led to compromised social and emotional wellbeing. This focus group-based research with provision of communal lunch however, played a part in addressing isolation, appreciation of social contact and limiting the psychological impact caused by COVID-19 lockdowns.

Keywords: HIV, COVID-19, isolation, community sector organisation

1 Introduction

Due to COVID-19 related lockdowns, as with the rest of the population, people living with HIV were forced to use digital technologies to access health and social care services and maintain social contact with friends and families. However, lockdowns and travel restrictions created isolation because of the necessity to self-isolate, socially distance, or shield to help control the spread of the virus and protect one's health and others. Lockdowns and strict social distancing/isolation restrictions consequently created unintended hardships resulting in some people living with HIV struggling to access basic amenities, including food, health and social care services [1].

The COVID-19 pandemic led to a reduction in HIV face-face testing between 2019-2020, but an increase in online testing through internet-based services was notable. A similar shift to virtual visits and consultations is noted in the United States of America, particularly for people living with HIV with higher medical and social needs [2]. In England, there were an estimated 97, 740 people living with HIV in 2020, of which 2,630 were new diagnoses. Around 4,660 were unaware of their infection, while at least 99 people with HIV died of COVID and co-morbidities [3]. The restrictions associated with COVID-19 led to people living with HIV experiencing several disruptions linked to diagnosis, treatment, and access to care. Face-to-face consultations were reduced by 32% to telecare which increased from 7,910 in 2019 to 59,280 in 2020. Due to the rapid shift to digital care, about 6,960 people were 'lost from the system' and not retained to receive continued care [3]. There may be several reasons for the reduction in retention to care.

Research reports that some people who use health and social care services have had little digital literacy making it difficult to access or navigate services or remain connected socially [1,4]. Digital divide or inequalities in digital access have been identified in some areas of England due to poor internet access. According to the Lloyds Consumer data, about 7% of homes in the UK are almost completely offline of which most are older adults. Concerns around poor internet connection, unaffordable broadband or lack of interest to engage in technology or simply not owning a digital device have also been barriers to a seamless shift to accessing services digitally. Digital villages tend to serve high-income earners living with HIV in larger cities. Older people particularly lack the skills to engage in telecare or new technologies and others may not have enough money to sustain internet connection.

O'Brien *et al.* (2021) [5] argued that disability, health disparities, interrupted access to services caused by the pandemic, increased substance use/ misuse, uncertainties around food and home insecurity and barriers to people living with HIV remaining engaged in care. For some, generally, it increased mental health problems due to illness, bereavement, stress and lack of support [6]. However, HIV support services have had to increasingly rely on differentiated service delivery

to simplify access to care and reduce worries around stigma, disclosure and adherence during the lockdown. Several studies identified increased role for community-based organisations in differentiated service delivery supporting the challenges faced by people living with HIV around access to antiretroviral medication, by delivering medication directly to people living with HIV, and optimise care continuum, address bureaucratic barriers linked to accessing hospitals and clinics, and provided counselling for example in China [7] and Zimbabwe [8]. Mpofu *et al.* (2021) [9] also identified the role of pharmacies in-home deliveries and collection of antiretroviral drugs in Botswana and that this also played a part in managing secrecy and stigma.

However, this need to socially distance, for people with HIV experiencing a syndemic, i.e. two or more epidemics interacting together, produces an increased burden of disease in people, increased levels of stigma, and mental health burden [10, 11]. HIV and COVID-19 have been linked to stigma. According to Marziali *et al.* (2020a and 2020b) [12, 13], people with HIV are at greater risk of experiencing social isolation due to HIV-related stigma, rejection or fear of rejection linked to HIV positive serostatus, and secrecy that prevents or restricts the establishment of social networks. Marziali *et al.* (2020a)'s study [12] with 770 participants reports that among participants with poor self-rated physical health, of whom 42% are living with HIV, 87% experienced loneliness compared to those with good health where 27% were HIV positive, 59% experienced loneliness. Nguyen *et al.* (2020) [14] argue that the direct effects of the COVID-19 lockdowns have contributed to lack of sleep, depressive symptoms, skipping meals, and financial challenges that have led to an inability to afford food and greater levels of loneliness social isolation among people living with HIV.

Through a qualitative study approach, the current study's main foci are to understand to understand the impact of COVID on those accessing community based HIV services, particularly with the view that services provided by the third sector moved support from face to face to telephone-based provision resulting in limited social contact or social activities, and to establish self-care and living strategies used by participants to cope through the pandemic.

2 Protection motivation theory

The Protection Motivation Theory (PMT) by Roger (1983) [15] argues that cognitive mediation process of behavioural change can be understood in relation to threats, coping appraisal, an estimation of perceived severity and vulnerability to contracting the disease. PMT claims that fear arousal influences attitudes and behaviour change through a calculation of the possible harshness of danger. As such, coping appraisal consists of expectations that undertaking certain actions will remove threats to contracting a disease and that self-efficacy and capability to act on recommended actions will prevent contracting a disease. PMT suggests that personal motivation for self-protection drives people to adapt protective behaviours against health threats where high vulnerability are perceived to be high with low rewards then there is a stronger motivation to engage in behaviours that promote good health [16]. As such, PM stimulates, sustains and guides actions aimed at protecting oneself from danger [17].

3 Methods

This study was part of an impact activity with people living with HIV accessing an HIV community support service, following the relaxation of lockdown two restrictions in England (July 2021). Legal limits on social contact was removed and indoor and outdoor social activities were permitted. The purpose of the event was to address isolation and provide space to address anxieties around re-integration within the community after the relaxation of lockdown restrictions but during a time when concerns about the COVID-19 pandemic continued. Participants were recruited through an HIV community based service that promoted the research and hosted the impact activity. Participants had the free will to take part in focus groups. A supportive, sensitive and kind environment was offered to participants making sure they were comfortable to share their experiences of life in the lockdown, coping strategies and peer support.

Nineteen participants took part, all above the age of 18, actively accessing services through an HIV community-based programme. Information sheets and consent forms were provided and only those who had fully understood the purpose of the research, felt emotionally able to take part, and signed consent for participation and publication of findings took part in the study. Participants could withdraw at anytime. The sessions took place at facilities provided by the service. Semi-structured open ended questions were used to guide discussions. These lasted up to sixty minutes, recorded using dedicated recording devices and later transcribed. Following this, a social event took place allowing participants to enjoy a communal lunch, socialise and reengage. A thematic analysis from the focus groups was conducted using a coding procedure to identify patterns between the groups and emerging themes [18].

4 Results

Interview data revealed themes including:

- (1) Loss of social connection offered by HIV support groups;
- (2) Challenged by the need to use digital technology;
- (3) Coping through COVID-19 restrictions.

4.1 Loss of social connection

All participants reported that attending this service provided a sense of community and belonging; it allowed them to have a social connection build and develop friendships. However, the COVID-19 pandemic lockdown enforced by the government forced them to lose face-to-face interaction, physical touch and social life that this particular service uniquely affords them. As with other HIV community-based services the service that was accessed by participants was also required to shift from face-face provision to tele-care, remote support or a brief doorstep visit to those with high social care needs, requiring food and dietary support. Consequently, those losing social contact and in-person support felt at loss socially:

My social connectivity coming here helped a lot. I've always been a very social person. I've always functioned better being part of a tribe. Lockdown was quite a challenge to me at a certain point when connectivity dropped. (Eli)

Obviously I found it really difficult. I was in the lunch club for schools and COVID hit. I got a letter from the government that I have to be shielding. I was then working from home and food was delivered through [this service] which was really lovely. I used to come for lunches before COVID. It was really a sense of having that routine and all of sudden it was gone. I had to find other ways. (Roni)

Pereira *et al.* (2021) [19] identified that people from the Lesbian, Gay, Bisexual and Transgender, Queer/Questioning backgrounds felt disadvantaged by the cancellation of events such as Pride with concerns that it led to a level of invisibility for people of minority sexual identities. Similarly, some of participants also felt that the cancellation of Pride negatively affected their sense of connection with the community of sexual minority people:

Because there's a lot of things that have stopped, my Pride. I love Pride and that's another thing that I felt was taken from me. I just used to love the solace it gives, the vibe and I'd see friends every so often to talk to. Not being allowed to meet up, meant, like, suddenly you don't see anybody. If you see somebody in the supermarket, you're frightened to say too much because you run the risk of talking about your vulnerabilities and disclosing your status when you really don't want to do that. (Harper)

For others the inability to have a holiday, or engage in their usual weekly social routines such as attending visiting a garden centres and meeting socially for lunch resulted in social isolation, low mood and compromised mental health. As reported:

I booked a holiday to go abroad. Two days after, the doors are closed, so I had to cancel it. I got a bit annoyed rather than upset. (Nolan)

Before lockdown, we would get to the garden centre for weekly lunch. I live in a flat and haven't got a garden. You then find you are not keeping fit anymore or doing what you usually do to stop feeling stressed. You get low, obviously not good for your mental health. It wasn't easy. (Aria)

Parisi *et al.* (2022) [20] identified that people with HIV experienced high levels of worry and anxieties about the risks of contracting COVID. This worry was increased by the initial confusion from Public Health England around whether or not people with HIV should shield. Some participants reported they had received letters encouraging them to shield. They were considered extremely vulnerable due to HIV in the absence of other illnesses in line with the COVID-guidance for shielding. Although this was corrected with British HIV Association and Terrence Higgins Trust confirming that there was no evidence determining whether people with HIV are at greater risk of contracting COVID-19 and that unless people with HIV were deemed extremely vulnerable they did not need to shield unless they had one or more conditions listed in the government's guidance for shielding. In this study, one participant in particular, expressed how they chose to shield anyway as this made them safe and less at risk of contracting COVID. Although he felt isolated, Everly was content :

I isolated myself because the whole world was saying bad things. And I thought that nobody is speaking about me. I felt isolated and I didn't want to reach out. I just wanted to be by myself; at the end of the day. The only thing I was really worried about

was the government's approach to the whole thing. I didn't want that pressure to be on anybody, not NHS so I just did it myself, so I just took it all in my stride. If I needed anything like food could get it from (HIV community service). COVID had put me in such a state that I didn't really want to be around anybody, I just wanted to be by myself and that's what I did. (Everly)

Across the focus groups, there was a sense that the lockdown generally 'increased that sense of loneliness in people' as noted by Vaughn who continued:

You've got all these things going on in the background which are affecting individuals and people in all sorts of different ways... If you get lonely, you get depressed. It's very easy to get depressed. Loneliness can be not very nice. I think a lot of people don't understand. I think, well, they're not well anyway. (Vaughn)

One participant spoke about his loneliness while with his partner during the lockdown period, suggesting that even those who had company, experienced loneliness:

I always thought you had to be very old to be lonely. I found, for me, I've got a partner but feel lonely. Nobody should be made to feel lonely or an outcast whether you are with your loved ones or not (Paisley)

Overall, most participants felt that COVID-19 lockdowns and the closure of non-essential public services, losing personal touch from face to face support offered by this service, postponement of social activities or excursions that offer a break, social contact, networking and social connectivity interrupted friendships, and family dynamics and also led to a sense of isolation. Applying the PMT, participants who followed the governments recommendations to self-isolate, or shield, were motivated to engage or adapt preventative behaviours to minimise risks of contracting COVID-19 although this came at a cost of social isolation.

4.2 Challenged by the need to use technology

The absence of face to face and physical contact forced some of participants to feel disengaged from family and friends. The World Happiness report by Okabe-Miyamoto and Lyubomirsky (2021) [21] identifies that the use of social media including voice, video and voice chat contributes to both positive satisfaction of life and wellbeing and for some, negative outcomes socially and emotionally. To improve social contact and a stronger sense of social connection during the lockdown, some of participants resorted to WhatsApp, telephone and other digital forms of communication and they found this helpful.

However, even with the increase in social contact with family, one participant felt the need to remain cautious about how much of their personal issues they needed to disclose. There was a sense across the groups that given the stigma around HIV, one needed to remain cautious about their HIV status and not fall into the trap of unwittingly disclosing due to increased social contact with family:

It disengaged from certain ways of keeping in touch and keeping social contact. I can use WhatsApp and I do use that, but there are some forms of technology that are partly age related, I think. I've found that since the beginning of lockdown I've started phoning relatives rather than my friends. I'm talking to everyone who's older than me or a bit older than me or 30 or 40 years older than me. I'm not saying too much about myself or my own issues in case I disclose. (Olis)

Even though a small number of participants were able to meet people through work, the absence of physical contact with family as well as inability to attend funerals made it difficult for one participant to deal with their loss:

For me, it's been very, very challenging. Even though I've been working all hours, more than usual because of Covid. I found it really challenging. Even though I have friends and we did Zoom and things and whatever. I like doing a lot of walking and just gardening. For me, going away is to see my family, my friends, so not being able to do that has been really difficult. One of my best friends died recently and I couldn't attend the funeral. It's been really, really tough to grieve and deal with that [upset]. (Addison)

As evidenced in existing literature, the pandemic has revealed the level of disparities in digital literacy in the country. Participants, particularly those above the age of 60 years, indicated that they lacked adequate knowledge to use platforms digital platforms to improve social contact. For some, the technology was new and too advanced and others, simply could not afford smart devices to enable them to enjoy video conferencing calls for example.

I'm a pensioner sort of thing, and I'm not able to put credit on the phone. I went to top up my phone. They said do you have a card. That was the first time I panicked. I've got a card for emergencies, you know, and I use cash money to get a taxi or blah, blah, blah. I've always had an old-fashioned phone and not the internet. I had to try to use WhatsApp. I've never heard of all that, but there you are, old-fashioned. Through all this it's helped me to learn how to use a phone, an up to date phone and took a little too long to learn. (Quinton)

However, the challenges of using digital technology was beyond social contact but practical day to day issues. Some participants explained how they struggled to shift from using public pay-point centres to settle utility using digital means:

I'm not computer literate. Like today 90% of the stuff you see advertised you're interested in, you've got a webpage you have to go to. My supplier for gas and electric, wanted me to do something on their website. I said, excuse me, I do not have access to a computer. I do not understand computers at all. I haven't got any knowledge of them. I said that there's a generation like myself, in my eighties. Surely, they could add a telephone contact to ask for what you want. (Pierce)

I went to a library to use a computer, I was petrified to be quite honest. The woman said to sit down, we're going to do this on this. Here's the mouse. Well, I didn't know what a mouse was. I said, what's that? I said, where's the mouse? She picked it up, it was right in front of me on the table. I felt so stupid. I said, I'm really sorry I don't know how to do this. She said, don't worry. But I still can't use it till now. I feel part of that has been robbed from me, not knowing how to do it. I feel a bit upset about it sometimes. I'm a physical person. I'm driving manually, you know what I mean? I have to learn everything else, but to have the square thing here and not know how to use it, it's harder as you get older. You really need someone by your side to actually tell you what to do. (Ramona)

These experiences reveal that COVID-19 led to people with HIV adapting the way they communicated with family, friends and other services. In some cases, it meant learning about technology in order to adapt to the new norm and to reduce vulnerabilities. These actions suggest individual self-efficacy and protection motivation in their coping responses. However for those who struggled to adapt easily due to lack of resources were negatively affected psychologically, practically and emotionally causing an impact on protective behaviours. Other studies identified that the government needs to provide resources and financial assistance to help those struggling so that they overcome the crisis caused by the pandemic.

4.3 Coping through COVID-19 restrictions

All participants reported that they found alternative activities that helped them to cope through the sense of isolation, for some it was loneliness or not feeling connected. Some participants like Kinsley enjoyed gardening and social contact through work and the gym:

For me, throughout the whole 15- or 15-months gardening and walking have been really important. When lockdown started with Zoom, I couldn't go to the gym. I've now joined a new gym. I was working as an HIV nurse I enjoyed seeing patients, you could mingle a little bit, chat a little bit, even if only for ten minutes whilst you were collecting your food, and that was really valuable. (Kinsley)

I also access services at XXX but I still felt safe enough to go and attend the exercise classes and the women's group and the day service there; there was a lot of support there as well. (Sadie)

In some studies, prosocial behaviour such as altruism in the time of a pandemic may continue to exist although due to people's defensive systems and fear of contracting a contagious virus might result in altruistic behaviours continuum depending on whether people see themselves as able to deal with the threat of a disease [22, 23]. Others found that altruistic behaviours associated with helping charities to fulfil their purpose can be motivated by one's desire to give back and reciprocate or a possibility of accessing the service in the future [24]. About a quarter of participants found themselves helping the service to deliver food to others through the door-step visit. This altruistic behaviour was mainly linked to reciprocity but participants in return were able to address social isolation through social contact with recipients of food packages:

I call to see if there's anything I can do for you, the shopping and that, bits and pieces for various people when they can't get out for walking, if they are vulnerable or shielding. With some of the people, I'm surprised they haven't asked for that help and

they haven't gone out. If I don't get out, I'll never move. You've sort of got three adults saying can I help, it's motivated them to do something for themselves. (Brooklyn)

Sometimes I had to do shopping for a relative. (Nevaeh)

The other thing I get a bit of gratitude for is, I know this might sound a bit draft, but we had that business all those months ago when everybody was banging on saucapan lid because I face up towards the hospital. One thing I get a lot of pleasure out of, any ambulances that go past slowly in the past, I always wave to the crew. A little gesture like that and they wave back to you and it makes them feel appreciated. People in any part of that health sector have been magic. It can't be easy what they go through, what I've witnessed, they're heroes [upset]. (Cloud)

Research by Ashbullby *et al.* (2013) [25] looking at the benefits of living in coastal regions Southwest England to families found that beaches encouraged individuals and families to be physically active. It contributes to positive psychological wellbeing including social interaction and stress reduction. All participants lived in and around a seaside town and they considered themselves privileged to have the beach in reach. Having the beach close by motivated some participants to walk. The perceived space, sea waves, beauty of the sea, and seeing others along the way were all considered refreshing and helpful with reliving feelings of stress of isolating:

Even if I couldn't get out to get food or something, the beach is five minutes away. I would take a quick walk to the beach and come home. For me it's being by the sea as well that appreciation of where we live. (Serenity)

I'm quite lucky because I live on the outskirts of XXX so once we were allowed to go out for an hour's exercise for me that was part of it. A new appreciation for the outside. You could actually enjoy, even if it wasn't going out into the countryside itself, just walking through your streets locally and a lot of people were still very much indoors and to re-familiarise yourself with your environment but also it was handy then because I would pick up takeaway food knowing that in the freezer there were some bits and pieces that I have, so you work up an appetite going for a nice long walk and then you didn't have to worry about necessarily cooking at the end of it. (Farrell)

I've been living on my own in the same flat for the several years, and I've found that if I get out and about, then get a coffee, sitting outside of a café on XXX or by the beach, I have got to know quite a lot of people over the years I've been doing it. It's nice just to see people that stop and you have a chat. This is very important to me in the fact that you meet up with people here (community based service), it's a very friendly, lovely atmosphere the moment you walk in. (Shud)

Other participants like Nevaeh and Sadie, enjoyed walking their dogs. Doing this contributed to feeling as though 'a weight was lifted off my shoulder and by the time you've walked with the dog, the dog ran over and made a fuss- it can be quite nice'. (Nevaeh)

For others, joining and taking part in social activities provided by other HIV support services broadened their social contact and support network:

I am part of the XXX Hub and Thursday, we do a virtual hub on Zoom where like we just have a natter and we just catch up and reach out with each other really. And then on Sundays we do a quiz, I'm not sure how that's going to roll in the future, but we do 2 meetings a week and it helps with socialising and support. (Nevaeh)

According to the PMT theory, those able to engage in coping appraisal responses that result in protection motivation would have identified the threat, its severity and sought coping strategies. Self-efficacy therefore would have led to participants taking control of their health by taking positive steps towards prevention and keeping safe during the pandemic.

4.4 Impact of the focus group

On the other hand, this research and communal lunch provided space for people living with HIV to socialise through focus groups, eating and sharing allowed people to reintegrate and limit psychological impact endured through the pandemic:

Coming here today has limited the psychological impact of the pandemic as well, as you said. Still getting socialising, talking, giving a purpose has been incredible. (Hailey)

Overall, engaging in alternative activities, appreciating the environment where one lives and the natural beauty and benefits it provided as well as learning and utilising technology to enjoy virtual contact with others helped most participants to cope during the lockdown, social isolation and social distancing measures associated with the COVID-19 pandemic restrictions.

5 Discussion

This study findings corroborate with other studies that identify that the COVID pandemic contributed to feelings of isolation and loneliness amongst people living with HIV. Unique to this study is the keenness of some of the participants to help others and be altruistic in supporting the purpose of the service by undertaking door-step food deliveries to meet the dietary and social needs of people living with HIV who were either shielding or unable to meet their own dietary needs. Their motivation was linked to the idea of reciprocity and 'giving back.' However, the benefit of their altruism was social contact and feeling less isolated.

These findings reflect that some people with HIV have struggled to access services due to their lack of knowledge or skill in using technology. However, they also demonstrate resilience, their ability to adapt to changing situations *e.g.* learning to use new technologies, their strength and ability to cope positively during the times of a pandemic or a crisis. The findings also demonstrate the importance and positive impact of HIV support services to people who are vulnerable and in need of extra support. These findings are supported by Cane (2018) identifying the important role of HIV support workers in social care.

6 Limitations

Limitations of the study relate to the focus group design approach we followed for this study and the that participants were recruited through a single service although the majority accessed other HIV services. Although participants were comfortable with each other and the venue of the focus groups and felt able to share their experiences, some participants had more to tell than others and left participants who are reserved to have lesser of a voice. However, to ensure all participants were given an opportunity to contribute, facilitators probed and encouraged all participants to contribute. Secondly, this research focused on experiences without looking at specific demographics, as such we were unable to consider differences in relation to age, gender, sexual orientation, financial status and other factors in the analysis.

However, the validity of findings is supported by other studies confirming the positive impact of HIV support services generally. We also believe this is the first study to explore the lived experiences of people living with HIV directly receiving support from a third sector agency, during the pandemic. The uniqueness of this study is the nature of service provided by this third sector agency during the lockdown and the dietary and social impact they had in providing food and addressing social isolation. This study adds to the growing research in the area of HIV support during the COVID-19 pandemic. Future research could include quantitative data, longitudinal experiences taking into account differences such as gender, sexual orientation, education and financial status.

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