Challenges and Lessons Learned through Initiating Patient Engagement with Migrant People Living with HIV During the COVID-19 Outbreak

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Abstract

Background: Patient engagement (PE) refers to the meaningful and active involvement of patients and other stakeholders (i.e. family members) in the conduct of research and transfer of knowledge. PE is usually an immersive experience for both stakeholders and researchers, based on direct dialogue and equitable partnerships. However, in reaction to the COVID-19 pandemic, social distancing measures have been introduced globally. These measures, which may remain in effect for a long duration, or be re-introduced periodically, prevent in-person gathering, and thereby, foster dependence on technologies to remain connected remotely. This affects PE methods. Thus, an understanding of how remote work affects PE is necessary.
Main Text
In this narrative, we present the experience of a research team that began engaging an advisory committee of recent migrant people living with HIV in Montréal, Canada, amidst social distancing measures put in place due to COVID-19. We highlight three major challenges faced by our team of researchers and the advisory committee. These challenges include (1) ensuring access to technology for both patients and researchers; (2) managing disclosure and comfort with online tools; and (3) creating meaningful communication and peer-to-peer rapport. Subsequently, we list the main lessons we gained through responding to these challenges: (1) the importance of allowing time, dialogue, and reflection to enable adjustment to the new context we are working in; (2) the need to evolve our teamwork dynamics; and (3) implementing hands-on experiences for patients is essential to establishing feelings of meaningful engagement

Conclusion: PE is not an easy task and its implementation can become even more complex amidst social distancing measures and other disruptions caused by COVID-19 (i.e. fear of contracting COVID-19). However, if appropriate methods are taken up, PE can serve as an instrumental pillar for research activities that seek to create an impact in communities and populations.

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Abstract (350 Words Max)

Background

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Keywords (3 to 10)

Patient Engagement, Patient-centred Outcomes Research, Participatory Research, Physical Distancing, Social Distancing, COVID-19, HIV Infection; Migrants

Introduction

Patient engagement (PE) is described as involving or collaborating with patients or other stakeholders (i.e. family members) in research.[1, 2] Meaningful PE should work towards actively involving patients in governance, priority setting, and the conduct of research, including the analysis of data and knowledge translation.[1, 2] PE can have great benefits for health research. It enables rapid knowledge dissemination to different concerned communities,[1] ensures relevancy of research to patients, improves outcomes through increased uptake of results,[3-6] and it increases trust and acceptance of research by patients and the public by bringing researchers to better explain the nature of the science they conduct.[7]

The importance of PE has been further demonstrated in the context of vulnerable and marginalized populations.[8-10] Indeed, PE enables researchers to counteract longstanding barriers encountered by people from racial and ethnic minorities, such as lack of information about or access to clinical trials.[8] It also provides ways to identify and tailor services to the needs of under-served communities and increases trust and confidence between public, researchers, and clinicians.[10, 11] PE usually takes the form of an immersive experience for all stakeholders and researchers (e.g., meetings, workshops), and is usually based on direct and equitable partnerships between groups. It thus requires qualities such as empathy, empowerment, and mutual understanding from all parties.[1, 2]

Nevertheless, the COVID-19 pandemic has disrupted the whole socioeconomic fabric and healthcare system, including healthcare services deemed non-urgent or non-essential. For chronic patients, including people living with HIV (PLHIV), links with care were reduced or suppressed for several weeks, with little access to healthcare professionals including pharmacists, treatments, community organizations, and loved ones, which in turn potentially increased their emotional, medical, or socioeconomic vulnerability.[12-17]

COVID-19 and social distancing measures introduced by governments have remained, to varying extents around the world, and are becoming part of a ‘new normal’. However, they complicate the immersive aspect of PE, challenging the dialogue and the sharing of patient experience and perspectives with researchers. The purpose of this narrative is to share our experience as a research team including a research coordinator (ARC), a research assistant with expertise in patient-oriented research (DL), and a PhD student (AA), initiating a ‘PE initiative’ with recent migrant PLHIV to Canada amidst social distancing measures.

Patient Engagement

PE Pre-COVID-19

Our research team has been engaging PLHIV in clinical research initiatives since 2016.[18, 19] PE in our research initiatives most commonly takes the form of advisory committee meetings attended by researchers, patients and/or other stakeholders (community members or representatives, healthcare professionals, etc.). Discussions usually consist of updates and deliberations about current research progress facilitated by a single PE agent (DL) or a research coordinator. Engaged patients are compensated ($50 CAN/meeting) and food and refreshments are provided.

The ASAP & Systematic Review Studies

In 2019, our team designed the Antiretroviral Speed Access Program (ASAP) Study, which aims to demonstrate the benefits of a multidisciplinary model of HIV care, alongside rapid ART initiation, on patient experience. The ASAP Study emerged from growing concerns at our clinic, the Chronic Viral Illness Services of the McGill University Health Centre (CVIS/MUHC), about the number of international migrant and newly-diagnosed PLHIV, especially asylum seekers and refugee claimants (ASRC), coupled with growing evidence that patients could benefit from a rapid (i.e., within a week) ART initiation. As a matter of fact, the number of ASRC culminated in Canada with 50,000 claims in both 2018 and 2019, with about half of them processed in Quebec.[20] ASRC in Canada must undergo an immigration medical examination including a mandatory HIV screening test. The proportion of newly-declared HIV cases attributable to the immigration medical examination has increased from 14-18% in 2010-2012 to 25-32% in 2013-2017.[21] The ASAP Study collects clinical, quantitative, and qualitative data, assessing a sample of new HIV patients' experiences of care, with the majority being migrants (>65%).

In September 2019, the first author (AA) joined the current research team as a PhD student. His doctoral program focuses on improving the care and education delivered to vulnerable and marginalized groups, including migrants via PE. As part of his PhD curriculum, he would work on ASAP complementary projects, beginning with a systematic review on barriers and facilitators to HIV care for migrants living in high-income countries (manuscript provisionally accepted with revisions in BMC Open).

In complement to these two studies, a Patient Advisory Committee (the ASAP & Migration Committee) was formed with four CVIS/MUHC patients, two of whom were ASAP participants, who expressed interest in being further involved in research. The two studies were initiated in February 2020 (upon receiving ethics approval from the MUHC Research Ethics Board). All Committee members are recent migrants in Canada (two international students and two refugees/asylum seekers) living with HIV, with two of them arriving in Canada 3-months preceding the initiation of the ASAP Study.

Initiating PE during the COVID-19 Outbreak

In reaction to the COVID-19 pandemic, the Quebec provincial government imposed social distancing measures on March 23,[22] requiring all 'non-essential' services or tasks to be provided or conducted remotely. Non-essential face-to-face meetings were prohibited. The ASAP Study provided participants with access to HIV medication and healthcare. It was deemed an essential service, and already-enrolled and new participants thus continued to attend care at the CVIS/MUHC. In-person interactions with participants were limited to healthcare providers. Hence, non-essential face-to-face research meetings with patients, including PE activities, were prohibited.

It was decided to still move forward with the PE initiative, but to adapt it accordingly. PE meetings were thus organized online. To date, we have held 5 meetings (Mar. 26, 2020; Mar. 30, 2020; Apr. 10, 2020; May 6, 2020; Jun. 25, 2020) on the Zoom video-conferencing software. Meetings were facilitated by the research team (ARC, DL, and AA). The coordinator prepared ASAP-specific discussion themes, while the PhD student prepared systematic review-related content. The research assistant communicated with and sent research material to patients via mail, email, and phone, depending on patient preferences or resources, confirmed meeting times, and compensated patients via online banking.

Challenge 1: Ensuring Access to Technology for Patients & Researchers

Several of us (researchers & Committee members) had poor quality laptops, cameras, smartphones, or printers at home; weak or unreliable internet connections; or no access to online banking. One patient partner had no internet access for several weeks. At times, lack of a strong internet connection led to some participants dialing-in to meetings. During these times, participants reported frustration or worry of missing out – particularly when items were being screen-shared. Overall, these technological issues impacted the fluidity of PE, reduced the overall quality of participation and depth of discussions, and resulted, at times, in feelings of exclusion.

Challenge 2: Managing Disclosure & Comfort with Online Tools

Participants (researchers & patients) felt insecure sharing their video on video-conferencing applications while they were in the privacy of their home or using more or less secured networks. Seeing one's image also made some participants self-conscious, or uncomfortable. These issues were exacerbated for members who felt concerned and vulnerable given their HIV and/or immigration statuses.

Challenge 3: Creating Meaningful Communication & Peer-to-Peer Rapport

We had difficulties communicating meaningfully and spontaneously with one another. Reasons include understanding when it is appropriate to speak, difficulties in interpreting verbal and non-verbal cues, and remaining focussed during video-conferencing sessions. Adding to these issues is the vast amount of cultural differences between all participants. Researchers and patients were from distinct ethnic, socio-cultural, and linguistic backgrounds and this could have affected our ability to understand one another.

Additionally, distractions in our respective home environments (i.e. family members entering/ exiting rooms) or on our computers (i.e. email notifications) hindered focus for all. Pauses and silences felt magnified in their awkwardness, understanding when one should speak and when another person is about to say something was confusing, and trying to establish a fluid conversation seemed more complicated than doing so in person. We felt that we spaced out or got tired quicker than in in-person meetings and after meetings, had more difficulty recalling the content of discussions.

Learning 1: Adjustments Require Time, Dialogue, & Reflection

Addressing these challenges taught us important lessons. We quickly came to a mutual understanding that these challenges were new for all of us and made a point of discussing them during meetings. With time, we all contributed to adjusting the way we practiced PE. During the first meetings, researchers found several solutions for participants with no or limited internet connection: they mailed research documents, encouraged participants to dial in meetings, and coordinated with CVIS/MUHC on-site staff to give participants cash compensations in hand during their regular consultations. During meetings, some participants closed their videos to avoid disclosure, others did so due to unstable connections, so they could at least hear the discussion. Through dialogue and better awareness of the features of the video-conferencing platform we were using, we implemented measures to ensure the confidentiality of meetings and respect participants' comfort levels: cameras were optional, we used a password to connect to the meetings, and made sure member names were not shown during meetings. We learned to accept silences while people were reflecting or taking time to absorb given information and to switch topics appropriately to maintain interest. In turn, discussions gradually felt more natural, fluid, and empathetic. Over time, participants became more comfortable and increasingly engaged in meetings with their camera on.

Additionally, with time, participants spontaneously took advantage of videoconferencing discussions to ask questions about the pandemic (e.g., why is Montreal the Canadian epicenter?) and HIV healthcare during social distancing measures (e.g., are pharmacies open?). They also shared COVID-19-related experiences of anxiety (e.g., fears of COVID-19 infection after a recent HIV diagnosis), isolation (e.g., difficulties in communicating with friends and families in their home countries), and public health measures (e.g., feeling stigmatized when wearing a mask in a store). The pandemic was in fact discussed at each meeting and functioned as a unifying conversation topic for which everyone had something to share. In response to these conversations, patient partners suggested the researchers include several COVID-19 and social distancing-related questions to ask in the ASAP Study interviews.

With respect to our cultural differences, our collective awareness of potential issues in communication due to remote work and our mutual differences made us actively attempt to learn from one another. Explicitly discussing our differences actually enriched our discussions, made them more immersive, and led us to redefine research priorities.

Learning 2: Teamwork Before, During, and After Meetings are Key

Remote work and videoconferencing redefined roles and increased interdependence and teamwork. Pre-COVID PE meetings were facilitated by one researcher as described above. During the COVID-19 outbreak, the three researchers spontaneously shared meeting preparation and facilitation tasks. To shorten meetings and reduce video-conferencing-induced fatigue, researchers collaborated to prepare questions and PowerPoint slides for participants; test technology and videoconferencing functions; and agree on ways to approach discussions based on their respective expertise and needs. During meetings, when one researcher experienced difficulties (e.g., when their internet connection was unstable), another could take over immediately or suggest solutions.

Also, when one facilitator animated a discussion, the two others took notes, which were shared with everyone after meetings. This shared responsibility for notetaking assisted all participants post-meetings as they gave everyone the ability to review, validate, and amend the notes if necessary. This reduced the impact of limited post-meeting recall. Using regular mail or email to share research documents and meeting notes also contributed to reinforce participants' feelings of inclusion. Overall, teamwork and post-meeting follow-up led to more engaged and time-sensitive meetings.

Lesson 3: Hands-on Experience in Research is Patient Engagement

Given the communicational challenges that we faced, and the time spent to discuss and solve challenges, researchers decided to shorten the time spent on discussing research and focus on tasks that participants could do alone, outside of meetings. AA thus prepared and delivered concise workshops on each step of the systematic review and gave participants the material to conduct each step (i.e., he provided articles for each participant to screen following specific inclusion/exclusion criteria and demonstrated how to do this). It was also decided that engaged patients would be compensated for the time spent on these activities.

Valorizing such hands-on experiences allowed us to shorten meetings to about 2 hours, and diversified participants' forms of involvement while developing their skills. One participant mentioned that being exposed to the scientific literature on HIV by working on the systematic review was comforting because he realized the breadth of efforts made to improve HIV treatment and care globally. Other participants mentioned that being engaged in this way provided them with a distraction in times of uncertainty and isolation, as well as a way to feel useful and access important information on HIV in Canada. All of this was particularly important to the patient-partners given their recent diagnosis and migration to Canada – two processes for which management was notably disrupted by COVID-19.

Conclusion

Amidst social distancing measures, PE virtual meetings enabled a space for support, co-creation of knowledge, and reciprocity between patients and researchers. For example, we quickly realized that the pandemic raised a series of issues that needed to be discussed with Committee members. These discussions, alongside serving as a means to relay patients (and through them, their network of other patients) key information about their HIV care delivery, also provided researchers with reflections and suggestions that ultimately improved ASAP qualitative data collection instruments.

Most social distancing measures remain in application at the CVIS/MUHC after the government lifted the lockdown in June 2020. In other words, the challenges that we are currently facing in adapting PE to our new social reality, and the solutions implemented, are likely to shape our behavior for a long time. Most notably: (1) technology is not a panacea – issues with and lack of it has forced our research team to adopt creative ways to ensure patient partners are able to continue their participation amidst social distancing measures (i.e. mailing research documents, dialing-in, evolving the facilitator team-work dynamic); (2) privacy, comfort, and rapport need to be redefined in this new context – but these can be achieved via open and respectful dialogue, time, and reflection; and (3) PE must adapt to stakeholders' needs and resources – in our case, facilitating concise workshops and engaging patients in conducting parts of the systematic review enabled feelings of meaningful involvement.

Before COVID-19, PE was already often reported to be time- and energy-consuming.[23-25] Measures that prevent in-person face-to-face meetings impact and raises new challenges in the planning and deployment of PE in research programs. Despite this, PE can be adopted and adapted to serve as an instrumental pillar for research activities that seek to create a community and population-based impact. In this regard, it is important that PE practitioners share their experience of creating meaningful spaces for dialogues and partnerships with patients and stakeholders, amidst our new social and work context.

List of Abbreviations

ART: Antiretroviral Therapy
ASAP: Antiretroviral Speed Access Program
ASRC: Asylum Seekers and Refugee Claimants
CVIS/MUHC: Chronic Viral Illness Services of the McGill University Health Centre
HIV: Human Immunodeficiency Virus
PE: Patient Engagement

Declarations

Ethics Approval and Consent to Participate

Ethics approval was obtained from the McGill University Health Centre (15-188-MUHC, 2016-1697, eReviews 4688).

Consent for Publication

All authors provide their consent for this publication..

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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Authors' Contributions

The first author conceived of this work. The article was primarily written by the first author. The second author also contributed to the writing of this article and provided significant advice and feedback to the first author. Authors three to seven provided substantial edits and comments to multiple drafts of this work.

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Supplementary Files