

## **“I have failed to separate my HIV from this pain”: The challenge of managing chronic pain among people with HIV**

This study/project is funded by the National Institute for Health Research (NIHR) [*Programme Development Grant, PRISM: Pain Relief Intervention using Self-Management RP-DG-0517-10004*]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

The authors have no competing interest to declare.

## **“I have failed to separate my HIV from this pain”: The challenge of managing chronic pain among people with HIV**

Pain is a highly prevalent and burdensome symptom among people with HIV (PWH). This study aims to identify how the experience of living with HIV and chronic pain influences pain beliefs, health-seeking and pain management. Thirty-nine purposively sampled PWH with chronic pain (sample characteristics= 61% women, 79% Black, Asian and minority ethnic groups, 18% men who have sex with men, 45-54 median age category) participated in one of six focus groups in London. Focus groups were co-facilitated with community members. Transcripts were inductively analysed using a thematic approach. Findings revealed that HIV stigma, fractured care pathways, and general practitioners' lack of HIV training are barriers to supported pain management. Unaddressed pain results in poorer mental health and reduced quality of life, which has important clinical implications for health service engagement and treatment adherence. Creating HIV-specific pain resources, activating social networks, and pain self-management techniques are potential solutions. Person-centred assessment and HIV training is needed to help clinicians identify PWH with chronic pain. Clear guidelines need to be developed to identify which health service providers are responsible for chronic pain management in PWH. This study generated a refined version of the Fear Avoidance Model that introduces a dimension of HIV-specific behaviours that impact PWHs seeking chronic pain management. Clinical pathways informed by our model have the optimal potential for success.

**Keywords:** HIV; chronic pain; pain behaviour, Fear Avoidance Model, HIV stigma, health seeking behaviour.

## **Introduction**

Pain is one of the most prevalent physical symptoms among people living with HIV (PWH), with a point prevalence of 54% - 83% (da Silva et al., 2017; Parker et al., 2014) over a three month recall period. Chronic pain among PWH has clinical implications due to its association with poor antiretroviral therapy (ART) adherence and regimen changes, missed clinic appointments and HIV viral rebound (Clucas et al., 2011; Harding et al., 2010; Safo et al., 2017; Sherr et al., 2007). Pain assessment and management have recently been reintroduced as a hallmark of good quality modern treatment and care (*British HIV Association: Standards of Care for People Living with HIV 2018*, 2018). However, in the UK, the priorities of HIV care continue to relate primarily to ART and the monitoring of blood results while other concerns, including pain, are considered as peripheral and are overlooked (Bristowe et al., 2019). PWH are encouraged to seek care for their pain in primary care as general practitioners (GPs) are the gatekeepers to specialist and pain management resources.

Chronic pain in PWH is attributed to the legacy effects of advanced HIV disease (Chen et al., 2013; Evans et al., 2011). Additionally, the cohort of PWH is ageing. PWH who are ageing, especially those with a long history of HIV infection, report frequent comorbidities such as musculoskeletal pain and episodic disability (Cuzin et al., 2017; Solomon et al., 2014; Walker-Bone et al., 2016).

There are psychological and social implications of living with HIV and chronic pain. A recent systematic review found that persistent pain among PWH is associated with greater severity of depression, psychological distress, post-traumatic-stress, and sleep disturbance (Scott et al., 2018). HIV and chronic pain are independently associated with poorer mental health (Merlin et al., 2014). Poor mental health affects pain intensity and ability to manage pain, and leads to decreased HIV adherence and

viral suppression (Mellins et al., 2003; Pence, 2009; Turner et al., 2002). Chronic pain also impacts activities of daily living and is linked with poor quality of life (da Silva et al., 2017; Harding et al., 2012).

Given the high prevalence and burden of chronic pain among PWH, and the accompanying psychosocial and clinical implications, clinical pathways to pain management are needed for this population. To enable PWH to better manage chronic pain, it is necessary to understand the behavioural mechanisms which lead to poor pain management and poor outcomes for chronic pain. This study explored how living with HIV and chronic pain influences pain beliefs, health-seeking activities and pain management.

## **Methods**

Qualitative cross-sectional focus groups were conducted with purposively sampled PWH. The study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ)(Tong et al., 2007). Ethical approval was granted by Kings College London; Psychiatry, Nursing and Midwifery Research Ethics Subcommittee (HR-17/18-6742).

### ***Recruitment and data collection***

Researchers collaborated with the UK Community Advisory Board (UK-CAB) to identify potential participants through two routes. First, participants were recruited through the UK-CAB's online forum. A community representative was the first point of contact for those PWH who expressed interest in participation. Second, HIV advocacy organisations, affiliated with the UK-CAB, recruited participants from within their membership and provided community venues for the focus groups.

PWH aged at least 18 years, with chronic pain as defined by the International Association for the Study of Pain (i.e. living with ongoing pain for more than three months) were eligible for the study (H. Merskey and N. Bogduk, 1994.). Participants were purposively targeted and sampled based on their self-described identities as men who have sex with men (MSM) and/or those of Black, Asian and minority ethnic (BAME) background, particularly BAME women, to ensure that the key populations of PWH in the UK were represented. Participants were asked to answer the following questions to assess eligibility for a focus group.

1. Have you been experiencing ongoing physical pain for more than 3 months?
2. Have you received a positive HIV diagnosis?
3. Which of the following focus groups would you feel most comfortable attending; a group for MSM, a group for BAME, a group for women?

Participants recruited through HIV organisations attended focus groups at community venues; those recruited online attended focus groups at university premises. The semi-structured topic guide, developed with community members, explored participants' experience of 'total pain' (i.e. a holistic approach integrating physical, psychological, social and spiritual dimensions) (Clark, 1999). Questions on the survey explored the practices participants currently employ to manage chronic pain, their access to formal services and resources, and sources of support. Participants gave written consent and self-completed a socio-demographic form. Focus groups were co-facilitated by a researcher and a community representative.

### ***Data management and analysis***

Focus groups were recorded using an encrypted digital recorder, transcribed verbatim, and transcripts pseudonymised. NVIVO software version 12 was used for

data management and analysis. We used an inductive thematic approach following Braun and Clarke's method (Braun & Clarke, 2006). Two researchers generated an initial coding frame, then presented the coding frame to steering group members, which included community representatives, for refinements. Disagreements were resolved by reviewing data together and creating clear definitions for codes. An iterative approach to analysis was undertaken. Themes and sub-themes were defined ensuring clarity and the breadth of views and experiences within codes were summarized. Quotes were selected from across the sample to illustrate themes.

Following inductive generation of themes, we used the data to make recommendations for better clinical pathways to pain management for PWH. We identified the Fear Avoidance Model as a theoretical model (Crombez et al., 2012; Vlaeyen & Linton, 2000) that illustrates the how pain behaviours impact chronic pain management (Crombez et al., 2012). We mapped our findings onto the Fear Avoidance Model to create an adapted model that was specific for PWH and chronic pain.

## **Results**

### *Sample Characteristics*

Thirty-nine PWH each participated in one of six focus groups (see Table 1). These comprised two women's groups (n=5 and n=13 participants per group), one BAME men's group (n=8), a mixed gender BAME group (n=5), a MSM group (n=3), and one mixed group with participants from BAME and MSM communities (n=5). Individuals self-selected the focus group that they felt best represented their identity.

The median age of the participants was 45-54 (Table I), 61% were women, 79% identified as BAME and 18% as MSM. Almost two-thirds (61.5%) said they found it

difficult or very difficult to live on their current income. The mean number of years lived with HIV was 18, and 84% of participants were on ART.

Table 1:

### ***Themes***

The following themes were identified: 1) Fear of HIV disclosure and stigma resulted in avoidance of chronic pain management support; 2) Lack of GP training and fractured care pathways resulted in unaddressed pain; 3) The psychosocial and clinical implication of unaddressed pain; and 4) HIV specific resources are needed for long term pain management. Illustrative quotes are presented in Table 2 (T2).

Table 2:

### ***Theme 1: Fear of HIV disclosure and stigma resulted in avoidance of chronic pain management support***

#### ***Pain is linked to HIV***

Participants stated that their HIV and chronic pain were inextricably linked as they believed that HIV or its clinical effects had caused or exacerbated their pain (T2:Q1,Q2). Participants developed negative, catastrophizing beliefs about how seeking support for pain would lead to disclosure of HIV and associated stigma. These thoughts created significant barriers to pain support from social networks and health care services.

Participants felt that to talk about their pain experience, they must be able to discuss HIV without stigma. If the general public, particularly health and social care professionals, were more informed and accepting of HIV, PWH felt it would be easier to seek pain support (T2:Q3).

### *Avoiding social support*

PWH feared discussing chronic pain and seeking support from their social networks as they were concerned about disclosing their HIV status (T2:Q4,Q5). The episodic nature of chronic pain created anxiety around socialising, as participants were unable to predict when the pain would occur. They were concerned that a demonstrable presentation of pain would lead to questions about its cause, and potential assumptions about the aetiology (T2:Q6). Participants often avoided social interactions to prevent stigma and discrimination causing social isolation.

### *Avoiding pain services*

Participants feared attending pain management services that were not specific to PWH, worrying about how they would be perceived by healthcare professionals, and about being required to disclose their status to more individuals (T2:Q7Q8). When accessing primary care, participants also mentioned concern about disclosing their HIV status (T2:Q9). Disclosure caused more distress when PWH had not established a prior relationship with the professionals.

*Theme 2: Lack of GP training and fractured care pathways resulted in unaddressed pain.*

### *Lack of GP training in HIV*

Participants described their poor relationship with their GPs (T2:Q10.Q11), feeling that their GP's were ill-equipped to treat PWH for pain because they lacked training in HIV (T2:Q12). Individuals frequently had to explain and educate healthcare professionals about HIV before receiving suitable treatment for their chronic pain. Most participants did not have continuity of care with a single GP and saw a new GP at each



appointment (T2:Q13). GPs wasted time by focusing on the disclosure and discussion of HIV which, owing to short appointments, left little time for the successful treatment of the participant's chronic pain, the whole purpose of their appointment (T2:Q14,Q15).

#### *Fractured care pathways*

Participants described GPs as assuming chronic pain was due to the patients' HIV. GPs were hesitant to treat chronic pain and would often refer participants to their HIV consultants (T2:Q16). But often chronic pain was considered to fall outside the speciality of HIV consultants, so participants were then referred back to their GPs (T2:Q17,18). This blurring of the responsibility for pain management between HIV and primary care services left participants untreated and feeling unsupported.

#### *Theme 3: The psychosocial and clinical implication of unaddressed pain*

##### *Poor mental health and reduced quality of life*

Unaddressed pain led to participants feeling depressed and hopeless. Without having a way to control their pain, participants described how the pain could overwhelm them (T2:Q19). Some participants explained that pain had caused them to have suicidal thoughts (T2:Q20,21). Social isolation, leading to lack of social support, had a significant impact on participants' mental health and their chronic pain (T2:Q22).

##### *HIV clinical implications*

Unaddressed pain also had implications for the participants HIV clinical care as it made some participants question their need to take HIV medication (T2:Q23). Participants felt that the HIV medical community was too focused on the ability of ART to extend life expectancy. They believed that to live a long life was not enough; they

also wanted to have a better quality of life, which could not be achieved with unaddressed pain. Participants questioned the point of living longer with HIV if they would not be living a relatively pain-free life (T2:Q24).

#### *Theme 4: HIV specific resources are needed for long term pain management*

##### *Acceptance and successful pain management*

Some participants demonstrated how they had learned to accept and manage their pain through distraction of routines, hobbies and social connections (T2:Q25,26). However, it was noted that to manage pain long term, PWH need access to resources to have the tools, self-management strategies and mental strength.

##### *Resources*

Learning to accept HIV was essential for pain management because of the large barrier played by HIV stigma in restricting access to pain support. Participants described how HIV tailored self-management courses had helped them come to terms with their diagnosis (T2:Q27). BAME participants, in particular, discussed the value of HIV peer-support groups in pain management, as PWH were able to share their chronic pain experience without fear of discrimination while also benefitting from a social network (T2: Q28,29).

Some participants illustrated how access to courses and pain clinics had provided them with the tools to self-manage their pain and communicate better with health care providers (T2:Q30,31,32). Holistic services (including acupuncture, massage, yoga, and mindfulness meditation) and supplementary therapies (including physiotherapy, hydrotherapy and chiropractic services) were also resources that some

participants had used to reduce pain, though these typically gave only temporary relief (T2:Q33).

#### *Barriers to pain resources*

Participant's found it difficult to manage their pain using complementary and holistic services because of their inconsistent access to these services. Some participants blamed funding cuts as the reason they couldn't access these services (T2: Q34).

BAME participants had less access to resources compared to their white peers. BAME participants notably identified cost as a reason for not being able to access holistic services and supplementary therapies (T2:Q35,Q36). Additionally, while all of the white participants in our sample had been referred to additional pain services through their GPs, this was not true for BAME participants, especially women: in the focus group with 13 women, only one had been referred to additional pain management services (T2:Q37).

#### ***Adapting the Fear Avoidance Model for PWH***

Figure 1:

The Fear Avoidance Model describes how individuals experiencing pain can become trapped in a cycle of suffering by developing negative, catastrophizing beliefs about pain, which then create a fear of pain resulting in activity avoidance (Vlaeyen & Linton, 2000). However, fear and avoidant behaviours result in further disability, and depression which negatively impacts the pain experience. The Fear Avoidance Model hypothesises that reducing fear and confronting pain will lead to pain relief. We mapped the themes and sub-themes identified in our analysis onto the Fear Avoidance Model to

create an adapted model, as seen in Figure 1, to add the dimensions of HIV that impact the chronic pain management experience for PWH.

## **Discussion**

Recent UK studies have identified pain as a major concern among PWH (Bristowe et al., 2019), however PWH are less likely to visit their GP for pain-related reasons than HIV-negative controls with chronic pain (Sabin et al., 2018). Our findings illuminate how PWH lack confidence in the ability of health services to manage their pain due to unproductive appointments where GPs prioritised general discussions about HIV over chronic pain. The study revealed that there were no clear guidelines concerning whether a GP or HIV specialist should be managing PWH pain. Instead the burden of navigating health systems and advocating for pain services fell on patients. Fractured care pathways required patients to disclose their HIV status to multiple health professionals, making them feel vulnerable to HIV stigma, a known barrier to healthcare utilization (Hunt et al., 2017).

Unaddressed chronic pain threatens to undermine the advances that HIV treatments have made to the wellbeing of PWH. Poor mental health, resulting from unaddressed pain, can impact the ability of PWH to manage their HIV and chronic pain. Additionally PWH with chronic pain are at risk of becoming isolated from essential social networks that support ART adherence and good psychological outcomes (Earnshaw et al., 2015; Vanable et al., 2006). Pain and symptoms are associated with poor quality of life among PWH (Cooper et al., 2017). Participants questioned the benefits of living longer if they were not living well. These findings amplify the value of calls to add a fourth 90 to the United Nations (UN) 90-90-90 targets (i.e. 90% of those with HIV aware of their status, 90% of those diagnosed on treatment, and 90% of

those on treatment with viral suppression) (Lazarus et al., 2016), requiring that PWH also have good health-related quality of life (Lazarus et al., 2016).

This study illuminated significant barriers to existing pain management resources. PWH were not able to manage their pain using complementary and holistic therapies due to cost and inconsistent availability. Self-management resources can be useful to assist PWH to manage their chronic pain long term without relying heavily on unreliable services. BAME participant's unequal access to pain resource referrals, emphasises the importance of person-centred care, which should take into account cultural differences in the acceptance and interpretation of pain to avoid under-treatment (*British HIV Association: Standards of Care for People Living with HIV 2018*, 2018)

### ***Study sample***

The majority of the PWH who participated in the study were black women who, in the UK, are the second-largest demographic group living with HIV after MSM. The median age category of the participants was 45-54 and most had been diagnosed with HIV and initiated ART over a decade ago. This population had prolonged exposure to ART, including some participants who had used earlier formulations that had a more burdensome impact (Breivik et al., 2006; Moore et al., 2000). Potential sampling bias may have occurred through our use of community, rather than clinic, samples, however, clinic samples may have under-recruited BAME participants.

### **Conclusion**

We make several recommendations from our findings. First, our findings support the call for holistic, person-centred clinical pathways to increase the likelihood that PWH will be able to successfully assess and manage chronic pain (Goodin et al., 2018; Merlin et al., 2014; Scott et al., 2018). Second, pain management interventions

should activate social networks and support self-management (which has some evidence for effectiveness among PWH) (Nkhoma et al., 2018). Third, clearer pathways must be established for pain management between primary care and specialist care (i.e. HIV services and pain services) with additional education for GPs on the management of non-HIV related conditions among PWH. Fourth, patient management must take into account the other conditions likely to be affected by pain, particularly mental health. Fifth, to ensure BAME PWH are accessing pain management resources, GPs should undertake implicit bias training, and pain management resources should be offered through trusted BAME HIV community networks.

The adapted Fear Avoidance Model provides a novel understanding of how the interactions between HIV stigma, fear-avoidant behaviour and chronic pain directly impact engagement with clinical services and clinical outcomes. The model also describes outside forces that can impact the behaviour of PWH with chronic pain and their ability to manage pain. If the findings and adapted model are acted upon, the potential for PWH with chronic pain to achieve the “fourth 90” – optimal quality of life – will be enhanced considerably.

Acknowledgements: We wish to acknowledge funding for this study from the NIHR Programmed Development Grant. We are grateful to HIV i-base and UK-Cab for their expert community input and assistance. We would specifically like to thank the African Advocacy Foundation and George House Trust for promoting the study and providing community venues.

## References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.  
<https://doi.org/10.1191/1478088706qp063oa>
- Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *European Journal of Pain (London, England)*, 10(4), 287-333.  
<https://doi.org/10.1016/j.ejpain.2005.06.009>
- Bristowe, K., Clift, P., James, R., Josh, J., Platt, M., Whetham, J., Nixon, E., Post, F. A., McQuillan, K., Ni Cheallaigh, C., Murtagh, F., Anderson, J., Sullivan, A. K., & Harding, R. (2019). Towards person-centred care for people living with HIV: what core outcomes matter, and how might we assess them? A cross-national multi-centre qualitative study with key stakeholders. *HIV Medicine*, 20(8), 542-554. <https://doi.org/10.1111/hiv.12758>
- British HIV Association: Standards of Care for People Living with HIV 2018. (2018). Mediscript Ltd. <https://www.bhiva.org/file/KrfaFqLZRIBhg/BHIVA-Standards-of-Care-2018.pdf>
- Chen, H., Clifford, D. B., Deng, L., Wu, K., Lee, A. J., Bosch, R. J., Riddler, S. A., Ellis, R. J., & Evans, S. R. (2013). Peripheral neuropathy in ART-experienced patients: prevalence and risk factors. *Journal of Neurovirology*, 19(6), 557-564.
- Clark, D. (1999). 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Social Science and Medicine*, 49(6), 727-736.  
[https://doi.org/10.1016/s0277-9536\(99\)00098-2](https://doi.org/10.1016/s0277-9536(99)00098-2)
- Clucas, C., Harding, R., Lampe, F., Anderson, J., Johnson, M., Edwards, S., Fisher, M., & Sherr, L. (2011). Doctor–patient concordance during HIV treatment switching decision-making. *HIV Medicine*, 12(2), 87-96.
- Cooper, V., Clatworthy, J., Harding, R., Whetham, J., & Emerge, C. (2017). Measuring quality of life among people living with HIV: a systematic review of reviews. *Health Qual Life Outcomes*, 15(1), 220. <https://doi.org/10.1186/s12955-017-0778-6>
- Crombez, G., Eccleston, C., Van Damme, S., Vlaeyen, J. W., & Karoly, P. (2012). Fear-avoidance model of chronic pain: the next generation. *Clinical Journal of Pain*, 28(6), 475-483. <https://doi.org/10.1097/AJP.0b013e3182385392>
- Cuzin, L., Katlama, C., Cotte, L., Pugliese, P., Cheret, A., Bernaud, C., Rey, D., Poizot-Martin, I., Chirouze, C., Bani-Sadr, F., Cabie, A., & Dat, A. S. G. (2017). Ageing with HIV: do comorbidities and polymedication drive treatment optimization? *HIV Medicine*, 18(6), 395-401. <https://doi.org/10.1111/hiv.12441>
- da Silva, J. G., da Rocha Morgan, D. A., Melo, F. C. M., Dos Santos, I. K., de Azevedo, K. P. M., de Medeiros, H. J., & Knackfuss, M. I. (2017). Level of pain and quality of life of people living with HIV/AIDS pain and quality of life in HIV/AIDS. *AIDS Care*, 29(8), 1041-1048.  
<https://doi.org/10.1080/09540121.2016.1274013>
- Earnshaw, V. A., Lang, S. M., Lippitt, M., Jin, H., & Chaudoir, S. R. (2015). HIV stigma and physical health symptoms: do social support, adaptive coping, and/or identity centrality act as resilience resources? *AIDS and Behavior*, 19(1), 41-49.  
<https://doi.org/10.1007/s10461-014-0758-3>
- Evans, S. R., Ellis, R. J., Chen, H., Yeh, T.-m., Lee, A. J., Schifitto, G., Wu, K., Bosch, R. J., McArthur, J. C., Simpson, D. M., & Clifford, D. B. (2011). Peripheral

- neuropathy in HIV: prevalence and risk factors. *AIDS (London, England)*, 25(7), 919-928. <https://doi.org/10.1097/QAD.0b013e328345889d>
- Goodin, B. R., Owens, M. A., White, D. M., Strath, L. J., Gonzalez, C., Rainey, R. L., Okunbor, J. I., Heath, S. L., Turan, J. M., & Merlin, J. S. (2018). Intersectional health-related stigma in persons living with HIV and chronic pain: implications for depressive symptoms. *AIDS Care*, 30(sup2), 66-73. <https://doi.org/10.1080/09540121.2018.1468012>
- H. Merskey and N. Bogduk. (1994.). *Part III: Pain Terms, A Current List with Definitions and Notes on Usage Classification of Chronic Pain, Second Edition, IASP Task Force on Taxonomy*, . IASP Press,.
- Harding, R., Clucas, C., Lampe, F. C., Leake Date, H., Fisher, M., Johnson, M., Edwards, S., Anderson, J., & Sherr, L. (2012). What factors are associated with patient self-reported health status among HIV outpatients? A multi-centre UK study of biomedical and psychosocial factors. *AIDS Care*, 24(8), 963-971. <https://doi.org/10.1080/09540121.2012.668175>
- Harding, R., Lampe, F. C., Norwood, S., Date, H. L., Clucas, C., Fisher, M., Johnson, M., Edwards, S., Anderson, J., & Sherr, L. (2010). Symptoms are highly prevalent among HIV outpatients and associated with poor adherence and unprotected sexual intercourse. *Sexually Transmitted Infections*, sti. 2009.038505.
- Hunt, J., Bristowe, K., Chidyamatare, S., & Harding, R. (2017). 'They will be afraid to touch you': LGBTI people and sex workers' experiences of accessing healthcare in Zimbabwe-an in-depth qualitative study. *BMJ Glob Health*, 2(2), e000168. <https://doi.org/10.1136/bmjgh-2016-000168>
- Lazarus, J. V., Safreed-Harmon, K., Barton, S. E., Costagliola, D., Dedes, N., Del Amo Valero, J., Gatell, J. M., Baptista-Leite, R., Mendao, L., Porter, K., Vella, S., & Rockstroh, J. K. (2016). Beyond viral suppression of HIV - the new quality of life frontier. *BMC Medicine*, 14(1), 94. <https://doi.org/10.1186/s12916-016-0640-4>
- Mellins, C. A., Kang, E., Leu, C. S., Havens, J. F., & Chesney, M. A. (2003). Longitudinal study of mental health and psychosocial predictors of medical treatment adherence in mothers living with HIV disease. *AIDS Patient Care and STDS*, 17(8), 407-416. <https://doi.org/10.1089/108729103322277420>
- Merlin, J. S., Zinski, A., Norton, W. E., Ritchie, C. S., Saag, M. S., Mugavero, M. J., Treisman, G., & Hooten, W. M. (2014). A conceptual framework for understanding chronic pain in patients with HIV. *Pain Pract*, 14(3), 207-216. <https://doi.org/10.1111/papr.12052>
- Moore, R. D., Wong, W. M., Keruly, J. C., & McArthur, J. C. (2000). Incidence of neuropathy in HIV-infected patients on monotherapy versus those on combination therapy with didanosine, stavudine and hydroxyurea. *AIDS*, 14(3), 273-278. <https://doi.org/10.1097/00002030-200002180-00009>
- Nkhoma, K., Norton, C., Sabin, C., Winston, A., Merlin, J., & Harding, R. (2018). Self-management Interventions for Pain and Physical Symptoms Among People Living With HIV: A Systematic Review of the Evidence. *Journal of Acquired Immune Deficiency Syndromes*, 79(2), 206-225. <https://doi.org/10.1097/QAI.0000000000001785>
- Parker, R., Stein, D. J., & Jelsma, J. (2014). Pain in people living with HIV/AIDS: a systematic review. *Journal of the International AIDS Society*, 17(1), 18719.
- Pence, B. W. (2009). The impact of mental health and traumatic life experiences on antiretroviral treatment outcomes for people living with HIV/AIDS. *Journal of*



- Antimicrobial Chemotherapy*, 63(4), 636-640.  
<https://doi.org/10.1093/jac/dkp006>
- Sabin, C. A., Harding, R., Bagkeris, E., Nkhoma, K., Post, F. A., Sachikonye, M., Boffito, M., Anderson, J., Mallon, P. W. G., Williams, I., Vera, J., Johnson, M., Babalis, D., & Winston, A. (2018). Pain in people living with HIV and its association with healthcare resource use, well being and functional status. *AIDS*, 32(18), 2697-2706. <https://doi.org/10.1097/QAD.0000000000002021>
- Safo, S. A., Blank, A. E., Cunningham, C. O., Quinlivan, E. B., Lincoln, T., & Blackstock, O. J. (2017). Pain is Associated with Missed Clinic Visits Among HIV-Positive Women. *AIDS and Behavior*, 21(6), 1782-1790.  
<https://doi.org/10.1007/s10461-016-1475-x>
- Scott, W., Arkuter, C., Kioskli, K., Kemp, H., McCracken, L. M., Rice, A. S. C., & de, C. W. A. C. (2018). Psychosocial factors associated with persistent pain in people with HIV: a systematic review with meta-analysis. *Pain*, 159(12), 2461-2476. <https://doi.org/10.1097/j.pain.0000000000001369>
- Sherr, L., Lampe, F., Norwood, S., Leake-Date, H., Fisher, M., Edwards, S., Arthur, G., Anderson, J., Zetler, S., Johnson, M., & Harding, R. (2007). Successive switching of antiretroviral therapy is associated with high psychological and physical burden. *International Journal of STD and AIDS*, 18(10), 700-704.  
<https://doi.org/10.1258/095646207782193821>
- Solomon, P., O'Brien, K., Wilkins, S., & Gervais, N. (2014). Aging with HIV and disability: the role of uncertainty. *AIDS Care*, 26(2), 240-245.  
<https://doi.org/10.1080/09540121.2013.811209>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.  
<https://doi.org/10.1093/intqhc/mzm042>
- Turner, J. A., Jensen, M. P., Warm, C. A., & Cardenas, D. D. (2002). Catastrophizing is associated with pain intensity, psychological distress, and pain-related disability among individuals with chronic pain after spinal cord injury. *Pain*, 98(1-2), 127-134. [https://doi.org/Pii\\_S0304-3959\(02\)00045-3](https://doi.org/Pii_S0304-3959(02)00045-3)
- Doi 10.1016/S0304-3959(02)00045-3
- Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior*, 10(5), 473-482.  
<https://doi.org/10.1007/s10461-006-9099-1>
- Vlaeyen, J. W., & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain*, 85(3), 317-332.  
[https://doi.org/10.1016/s0304-3959\(99\)00242-0](https://doi.org/10.1016/s0304-3959(99)00242-0)
- Walker-Bone, K., Doherty, E., Sanyal, K., & Churchill, D. (2016). Assessment and management of musculoskeletal disorders among patients living with HIV. *Rheumatology (Oxford, England)*. <https://doi.org/10.1093/rheumatology/kew418>

## Table Captions

Table 1: Sample Characteristics

Table 2: Illustrative quotes from the focus groups

## Figure Captions

Figure 1: The adapted Fear Avoidance Model for PWH and chronic pain based on the findings.