ABSTRACT

Previous data from South Africa have suggested that people living with HIV (PLWH) and chronic pain remain as physically active as PLWH without pain, possibly due to HIV stigma. Additionally, HIV stigma may motivate PLWH not to disclose their pain, which was hypothesised to reduce the ability of PLWH to recruit social support. This mixed methods study explored factors influencing pain and activity, including pain disclosure and social support, in rural South African women living with HIV (WLWH). Firstly, quantitative methods were used to determine the prevalence and clinical and demographic associations with both pain and pain intensity. The Brief Pain Inventory was used to assess pain prevalence, intensity, and location in 125 women. Pain prevalence was 50% (63/125). HIV status, age, education, employment, current CD4+ T- cell count depressive symptoms were not associated with pain (ps>0.05). Education, employment, and HIV status did not associate with pain intensity. The pain was of moderate to severe intensity (5(4-6)) (median (IQR)). The most common pain sites were the chest (33%) and lumbar spine (24%). Secondly, from the 125 women recruited, twenty WLWH with pain (10) and HIV without pain (10) were recruited for in-depth, semi-structured qualitative interviews to explore beliefs about pain, factors influencing activity, disclosure of pain and social support. Qualitative interviews were transcribed and analysed using thematic analysis. Severe pain episodes caused a high interference with activity in WLWH and pain. Pain disclosure was high (9/10) and motivated by the need for social support. HIV stigma and fear of others' reactions did influence pain disclosure. WLWH did not disclose to everyone (selective disclosure) or did not inform people timeously of painful periods (partial disclosure). Disclosure to health professionals was motivated by the need for pain treatment. Disclosure of pain typically led to increased social support (7/10), such as disclosure targets taking over their duties of daily living. Participants felt liberated after disclosure (6/10), but negative impacts of disclosure included emotional impact (worry, sadness) on those disclosed to (6/10) and participants feeling like a burden (2/10). Results from this first qualitative study on pain in rural South African WLWH and pain elaborate on previous findings. That is, the pain did affect activity in women but only during painful episodes. Women were highly likely to disclose their pain to others and thus were able to recruit social support. There were both positive and negative impacts of disclosing pain, and WLWH tried to prevent negative impacts by selectively or partially disclosing their pain to others.