Abstract:

Background since the 1980s the Majengo Observational Cohort Study (MOCS) has examined sexually transmitted infections, in particular HIV/AIDS, in a cohort of sex workers in Majengo, an impoverished urban village in Nairobi, Kenya. The MOCS investigators have faced criticism since the women have remained in the sex trade for the duration of their participation in the study, prompting concerns about exploitation. Yet despite these concerns, the cohort has survived for almost 30 years. Methods In this retrospective qualitative case study; we examine the community engagement practices of the MOCS and explore the factors that account for its durability. Results Women in sex work in Kenya were a highly stigmatized and disfranchised community. As a result, there was no natural 'community' of sex workers either in Nairobi or in the Majengo village. The Majengo clinic aimed to reduce the barriers to health care the women experienced at the STC clinic by bringing the services closer to them and by providing a non-discriminatory environment. The women acknowledged the fact they had hoped their participation in the MOCS would have helped them find a path out of the sex trade. But our findings also add another dimension to this debate, since every cohort member we interviewed expressed her gratitude for the deep impact the MOCS has had on her life, much of it beyond the improved health status made possible by access to quality healthcare services. Participation in the MOCS has improved and enriched their lives. The CE activities have played a central role in creating a community that did not exist independently of the MOCS. Conclusions our case study identified 3 distinct phases of community engagement in the MOCS: (1) reaching out: mobilization, dialogue and education; (2) foundations of trust through relationships of care; and (3) leveraging existing social capital to form a cohort community. The findings demonstrate the importance of some of the less obvious benefits of participation in research, namely the evolving experience of community and the accompanying gains in personal security and solidarity that have kept the women in the cohort, some for 20 years or more.