Stigma as a barrier to cancer palliative care outcomes among people with HIV in India

PIs: Maria L. Ekstrand PhD, Naveen Salins MD

Consultant: Richard Harding PhD

UCSF-based Project Staff: Elsa Heylen MA, Amanda Mazur MS

Project Description

Cancer incidence is rising among people living with HIV, as improved access to antiretroviral treatment has led to an increased life expectancy worldwide, including in India, thereby also increasing the need for palliative care services. While it is well known that HIV stigma acts as a barrier to engagement and retention in HIV care, we do not yet know how the additional stigma of cancer may compound this problem. The proposed study would meet this need by adapting our current India HIV stigma measures and African palliative outcome measures for use among people living with co-morbid HIV and cancer in India, and to adapt a novel evidence-based African intervention to improve access to effective palliation and end-of-life decisions throughout the care continuum in India. This is a two year study conducted in collaboration with our colleagues at Kasturba Medical College, Manipal.

Specific objectives include:

Aim 1 use qualitative interviews to examine dimensions of stigma and their role in care across the care continuum among patients dually diagnosed with HIV & cancer, their family members, and health care providers.

Aim 2 the qualitative data will be used to adapt our existing HIV stigma model and palliative care outcomes measures, by adding the unique perceptions and experiences reported by PLWH with cancer

Aim 3 Test the new HIV/cancer stigma model, by administering the adapted measure to a sample of 80 PLWH, 80 cancer patients, and 80 patients diagnosed with HIV & cancer to examine potential barriers to effective cancer palliative care, the association of stigma with psychological distress, care engagement and outcomes.

This model will be subsequently be used to modify our low-cost, scalable health care provider intervention, shown to significantly improve palliative care outcomes in Africa and to test this in a future clinical trial. If successful, this could thus have a powerful and sustainable impact on palliative care outcomes in India.