

Living with HIV in Rural Areas: Finding Help and Empowerment with the MACS/WIHS Combined Cohort Study

By Queen Hatfield, WIHS NCAB Member

The MACS/WIHS Combined Cohort Study (MWCCS) is a collaborative research effort that aims to understand and reduce the impact of chronic health conditions that affect people living with HIV. MWCCS participants represent many demographics across the United States. Currently, there are 13 MWCCS sites, located in the following states: Mississippi, Georgia, Maryland, Pennsylvania, Alabama, Ohio, New York, California, North Carolina, Illinois, Florida and the District of Columbia. With this widespread of participants, the study literally goes from coast to coast. This allows the study to gather findings from multiple backgrounds and cultures.

In order for an HIV positive person to seek care, they have to be knowledgeable of the care that is needed. In the past, a positive HIV diagnosis was seen as a death sentence. Today, HIV is seen as a livable, chronic disease if the appropriate medication is taken. Along with medication, additional care is needed. Additional care can be mental health assistance, continuous primary care, or education for a healthier lifestyle.

Living conditions can play a major role in access to care. Living in an urban area could allow quicker access to doctors and effective diagnosis. Quick and accurate diagnosis allows an HIV positive person access to a treatment plan and opportunity for education. Living in a rural area can hinder access to efficient health care. In some cases, there may be a 20 minute to 2-hour drive to obtain care. Lack of transportation is a major obstacle to discourage individuals from seeking the care that is needed. Most rural towns are small, closely connected communities. This environment often creates privacy issues and workplace discrimination due to medical diagnosis.

A Case Study: Melody

“Melody” has been living with HIV for over 17 years. She has been able to lead a healthy and fulfilling life. However, her journey to get there has not been easy. It has been plagued with hardships and roadblocks in attempts to get the assistance needed while living in a rural area.

When Melody initially received her diagnosis, she immediately thought it was a death sentence. She received the news from a doctor’s office in her hometown. Some of her friends and family worked in that office. She was ashamed and did not want anyone else to know of her medical diagnosis. Melody had heard, firsthand, other friends and co-workers speak negatively about others with a positive HIV status. They called it “the package” and judged the lifestyles of those that were living with the disease. Melody did not want to live with the stigma of having HIV in a small town. She knew that some in her community would insinuate that she was on drugs or that she had several different sexual partners. Because she was already judging herself, Melody couldn’t carry the extra burden of being judged by others.

Melody chose to seek medical assistance outside of her hometown in an effort to maintain her privacy. Her commute to her doctors can range from 45 minutes to 1 hour. This was a welcomed option to avoid the local drugstore where classmates and friends are employed. Commuting to the city affords Melody the luxury of being completely open and honest with her doctors, without the fear of her personal life being spread around her local community. Melody found great help in the city. She found a compassionate primary doctor and has been receiving the best care for her depression and anxiety.

The small mindedness of some of the people in her community is still shocking to Melody. Their comments show how lack of knowledge is still a major issue in rural areas. She has heard her friends and co-workers state that they would not eat or drink behind a person who has HIV, as if doing so would make them instantly catch the disease. Melody understands that a person's lifestyle does not dictate if a person will contract HIV. She was careful and unfortunately still caught the disease.

Receiving assistance in her hometown is another unpleasant obstacle that Melody had to endure. Having been furloughed for the last three months due to COVID-19, seeking government assistance was a necessity. Melody had lost her health insurance and needed to purchase her medication. The government agency in her rural hometown wanted her to go through a lot of red tape. She would still be waiting on approval for assistance today had she not sought help in the city. Melody went to Jackson and received funding and medication through the Ryan White Foundation within two weeks. She also received housing assistance through another agency in Jackson. When seeking help in her hometown, no one at the agency seemed to have knowledge of what assistance she was seeking and what she was eligible for. They didn't seem to care to go the extra mile to figure it out.

The MWCCS staff helped motivate Melody to live. Their compassion and support made Melody feel like family. Each person in the program has a special place in Melody's heart. MWCCS helped Melody focus on her mental health and made her feel comfortable accepting herself. This study gives HIV positive individuals freedom to speak openly about their condition. It seeks to help and empower others. The findings from Melody's participation could possibly help lead to a cure.