

## **Murmurs: Stories from Our Journey in Medicine**

### **[Season 2, Episode 4: An Appreciative Inquiry Narrative](#)**

**By Ken Peterson**

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#### **AN APPRECIATIVE INQUIRY NARRATIVE**

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The mid to late 1990s was a particularly challenging time for primary care providers who managed patients with HIV/AIDS. During this period of time we saw patients die and we saw patients live. We experienced the fatal outcomes of a disease that initially had no cure while also experiencing successful outcomes of evolving antiretroviral medication regimens. In some instances, times were good and in other instances times were bad. I remember these days as stressful but I also remember these days as invigorating and hopeful.

As I think about these times, I remember my beginning practice as a family nurse practitioner for patients and families whom our society often considers less deserving. I remember the challenges I had as a novice primary care provider. I remember the joy I had in meeting and working with colleagues who had similar professional goals and desires for helping others in need. I remember my personal advances in knowledge acquisition and overall development. I mostly remember the people; those I collaborated with, those I learned from, those I shared stories with,

those I laughed with, those I cried with and most importantly those patients and families we so deeply and so intently cared for.

During this time I worked as a full time family nurse practitioner at a large federally qualified community health center. I saw patients with all sorts of acute and chronic health problems in both our primary care and urgent care clinics. Over a short period of time, say 3 years as a novice primary care provider, I became attracted to caring for our patients with HIV/AIDs. I took this attraction to a more rigorous level and with the support of colleagues and supervisors; I became the lead health center provider for our patients with HIV/AIDs. This new challenge and position allowed me the opportunity to work closely with our HIV/AIDS team that included consulting infectious disease specialists and an array of other care providers. I learned so much during the time. I attended local and national conferences. I met and enjoyed the company of so many people who shared common goals and desires for respecting and helping others and making this disease a thing of the past. I soaked up so much during this time. I truly felt that I had the capacity to lead and to collaborate and share knowledge and expertise.

We cared for many individuals with HIV/AIDS during this time. I remember in my panel alone of nearly 1000 patients that I had at least 30 patients who were HIV positive or had AIDS. I have full recollection of so many of them. I remember in detail many of their stories. I remember their good times and their bad times. I remember the impressions they left in heart and in my mind. I remember the day I made a home visit to a young women's apartment in GBV. She was one of the many patients whose disease state came too early in the epidemic for her to benefit from

the evolving HAART. She was so sick and so weak on the many occasions I saw her in the health center. She always tried to hide it though, I think mostly because she had 2 young children in her care. I remember she always talked about the future and the hopes she had for her son, then a middle school student and her daughter an elementary school student. I was always in awe. I am always in awe of patients who seem to hold so much together during such challenging and painful times.

The visit I made to their home that day was during the time she was quite debilitated and ultimately close to death. I think she only lived a week or two after the day I visited her home. One the day I visited her I hadn't realized what was ultimately going to result from this home visit, that I could use my strengths and experience to make a difference in a different kind of way. Prior to my NP career I had many experiences of visiting patients in their homes in my prior role as a home care nurse. I saw patients in very challenging housing situations that many would consider unlivable, but patients carried on in these environments the best they could. On this particular occasion, I arrived at her home, a concrete block, cold and dark apartment to find her alone with no help. She was very uncomfortable and lying on a couch. She had serious diarrhea and was incontinent of stool. She had next to her a 5-gallon bucket that she was using as a commode since she couldn't make it to the bathroom. Needless to say, I was shocked and so very sad to see her in such a state of deterioration. I must say that the 5-gallon bucket was what made the most impact on me that day. Here was a woman, a mother, a kind and loving individual, a resilient soul who remained strong on so many occasions where others would most certainly falter who had to sit on a plastic bucket in order to toilet herself in the final

days of her life. It seemed convenient, but it was a bucket and she was alone. I wondered what her children thought. I wondered how she felt about seeing their mother living out her final days with these conditions. I wondered if she wished her final days could be more meaningful and simply more comfortable.

Over the next day or two we worked very hard to negotiate details like insurance benefits and the like and we were able to make arrangements for her to live out her final days in a hospice house. It was a beautiful serene place next to a pond. Her room had sliding patio doors for her to view the ducks on the pond. There was a patio with Adirondack chairs overlooking flowers and trees. There were nurses and assistants there to help with her hygiene needs. The space was healing and comfortable a much better environment from her apartment in the projects and where her family could enjoy her and say goodbye, and a place where she could experience physical comfort in her last few days of life.

It was so enjoyable and meaningful for me to see her response and the family's response to her dying days in this type of environment; one in which supportive care and humane living conditions were present. I remember on a day that I visited the hospice...hearing her sister say to me...thank you...this is probably the mostly lovely place my sister has ever had the opportunity to reside in during her lifetime. Her children went on to be adopted by a social worker. I had lost touch with them and the last update I think was in 2009, but at that time I knew they were thriving. I have always hoped that the memories these children had of their mother's last days in life were made better from the opportunity we worked so hard to bring to them.

In March of this year on the occasion of my own children's' adoption day

anniversary, I received a Facebook invite from the social worker who adopted them. We connected and she brought me up to date. The children have done the best that can be expected given the tremendous experience of loss that occurred for them so early in life. They are now in their 30s. There's a grandchild and she's named after her grandmother. They think and talk about their mother to this day. She (the adoptive mom) recalled the visit her son then age 13 had with his mother in the hospice to say goodbye. She said she remembers it being calm and peaceful for the family and she also remembers how this peace and serenity helped him to verbalize his feelings as he said goodbye to his mother. He spoke to her in Spanish and said he would always love her and never forget her...that she would always be his mother. She then told me that she was sure the children would be happy to know that I carry on the memory of their mother in this way. She said she was grateful that they had us (several health center providers) during that difficult time.

I will always carry this memory and the experiences of all my patient encounters with me. I will always strive to do my best to provide compassionate care and to help others reach their highest potential regardless of where they stand in life's journey.