ORAL HISTORY INTERVIEW WITH JOHN BARTLETT
Duke University Libraries and Archives
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Researcher: Anthony Zhao

COLLECTION SUMMARY

This collection features an oral history I conducted with John Bartlett on January 29, 2024, for the Bass Connections Agents of Change oral history project. The 88-minute interview was conducted in the Duke Medical Center Library, in Durham, NC. Our conversation explored the early years of the first public HIV/AIDS clinic at Duke; experiences with stigmatization in the community; and the clinical trials for AZT, the first available treatment for HIV/AIDS. The themes of these interviews include community activism, health education, and patient-centered care.

This document contains the following:
- Short biography of interviewee (pg. 2)
- Timecoded topic log of the interview recordings (pg. 3)
- Transcript of the interview (pgs. 4-23)

The materials we are submitting also include the following separate files:
- Audio files of the interview*
    - Stereo .WAV file of the original interview audio
    - Mono .MP3 mixdown of the original interview audio for access purposes
- Photograph of the interviewee (credit: John Bartlett)
- Scan of a signed consent form

*At the end of the interview recording, we recorded a self-introduction and room tone for use in a production edit of the interview.

BIOGRAPHY

Throughout his career, Dr. John Bartlett has focused on the treatment of HIV, particularly in resource-limited settings. Alongside holding the position of Professor of Medicine, he is Director of the AIDS Research and Treatment Center, Professor of Global Health, Professor in the School of Nursing at Duke University, and Professor of Medicine at Kilimanjaro Christian Medical Centre.

Bartlett was raised in Rochester, New York. His mother was a nurse and his father a psychiatrist, and both were engaged with social action related to the Civil Rights Movement. At Duke in 1982, he saw AIDS for the first time; it was not just new to him, as a resident physician, but also to the entire medical world, which understood nothing about how it spread. In 1987, after completing his fellowship in infectious diseases, Dr. Bartlett had the opportunity to move into private practice, but instead he chose to stay and start Duke's dedicated public HIV/AIDS clinic, which he saw through significant adversity in its early years. In this public clinic, Dr. Bartlett cared for and later treated the underserved patients in the community. Duke was recognized as one of the nation's AIDS treatment evaluation units, where new therapies such as AZT were being tested. The research funding allowed him to build a "high functioning" interdisciplinary team to deliver "patient-centered care, [which] was a harbinger of what healthcare was going to become." From then onwards, Dr. Bartlett made sure that the combination of research and service was central to Duke's model. As HIV/AIDS became a more manageable disease for patients in the United States, Dr. Bartlett has turned his attention to the international AIDS epidemic over the past two decades, particularly in Africa where resources are limited, and where care, even in the early 2000s, was largely palliative.

For Dr. Bartlett, idealism "permeates [his] entire life" and this idealism compels him to go beyond "writing prescriptions … to be involved," and to "roll up [his] sleeves and become an activist." Compared to other contagious infectious diseases, it was obvious to Dr. Bartlett that HIV/AIDS was perceived differently because of its association with sex, poverty, the LGBTQ community, injection drug users, and prostitutes. This stigma caused a further increased fear of the risk of contagion not only in the community but also within the healthcare system. When others avoided his clinic in fear, Dr. Bartlett organized colleagues who shared his idealist belief in improving patient care for all HIV/AIDS patients. Although the stigma still lingers, Dr. Bartlett encouraged skeptical secretarial workers to interact with his patients in Howland Ward, and this completely changed their view on HIV. For them in the HIV ward and also for himself throughout his whole career working with patients, Dr. Bartlett found that "there is no question that personal contact and relationships are absolutely essential."

INTERVIEW TOPIC LOG (John Bartlett.wav)

00:00 Introductions
00:53 Family's background in medicine in Rochester, NY
02:14 Civil rights in Rochester, family involvement in civil rights movement
04:43 Family values
06:15 Societal changes in the 1960s, idealism as a mindset
08:30 Thinking about health disparities, African American housemaid in WV
13:04 Arriving at Duke in 1981 as a resident intern
14:55 Deciding to not join private practice, stay at Duke instead
17:53 Seeing AIDS patients at Duke as a resident and fellow, stigma from fear
19:35 Neglected AIDS patients, developing a list of trusted providers
21:31 Trying to educate colleagues about HIV infection, great frustrations, demonstrating to colleagues, story about accidental contaminated needle stick, great attention paid to prevention with AZT, teamwork
24:35 How stigmatization changed over time, story about secretarial pool in Howland Ward's developing relationship with clinic patients
28:25 Celebrities coming out with HIV, Magic Johnson
31:32 People who were reluctant to change their fearful mindset about HIV/AIDS
34:32 Diversity of patient-centered available at Duke, social work, access to clinical trials
35:55 Meetings with social workers, group therapy sessions for staff in the clinic
38:19 Overcoming sadness from working with dying patients, truly respecting them
42:18 Obstacles in providing home care to AIDS patients, personally transferring bodies
48:41 Relationship with LGBTQ community, sex worker community, Durham County Health Department volunteer work
51:05 Private versus public clinic at Duke, changing demographics of the HIV epidemic
54:55 Early challenges for the public HIV/AIDS clinic
57:01 Assembling the team of healthcare providers in the clinic
1:01:47 Meeting Julia Giner and Patricia Bartlett, developing relationships
1:05:59 Patricia's outspokenness, inspiring him to take difficult stances based on personal beliefs, involvement with political issues threatening to expose private patient data in 1988-89
1:11:59 Political environment and activism during the Reagan presidency
1:15:42 Thoughts and experience with speaking on behalf of communities affected by HIV
1:17:04 HIV/AIDS stigma, and why it is different than other diseases
1:19:50 AZT trial, ways that patients managed to unblind in solidarity and desperation
1:24:11 Mindset while being an idealist and activist
1:25:29 Mentorship at Duke

TRANSCRIPTION (John Bartlett.wav)

AZ 0:02
Okay, my name is Anthony Zhao. The date is January 29, 2024. We're recording in the Duke University Medical Library in Durham, North Carolina, and I'm interviewing Dr. John Bartlett.

JB 0:22
Thank you.

AZ 0:23
Yeah, I'm happy to have you here. I read your previous oral history, and I was interested in hearing more about those early days of HIV while you were here.

You told me that you both of your parents worked in health care. Do you think they encouraged you to join the field and start to do what you did, or they just let you do whatever you wanted?

JB 0:53
So, my father was a psychiatrist and a hospital administrator. He had a career in academic medicine at the University of Rochester. My mother was a psychiatric nurse. Certainly in that context, I had lots of exposure to medical issues, and to medical career pathways. But my parents did didn't necessarily encourage me to pursue a medical career, they would have been quite happy with any career pathway. They were extremely supportive, wonderful parents.

AZ 1:48
If they didn't expose you, or encourage you too much to do medicine, I also remember you told me that your parents exposed you to the social action activities that were going on at the time, when you were growing up with the civil rights movement. How did that work? Was it through just them? Was it through other family or friends, or the community that you grew up in?

JB 2:14
So I grew up in the 1960s. This was quite an exciting time in United States history. We were witnessing the civil rights movement. When I grew up, segregation, even in Rochester, New York was quite common. It was common for facilities to have separate bathrooms for white people and African American people. They also had separate drinking fountains for white people and African American people. In the hospitals, wards were segregated by race, and witnessing this terrible circumstance, an inexcusable circumstance, in a country where everyone was created equal, fostered a sense of great concern and unease, and so as a consequence, my parents were involved in the Civil Rights Movement. My father was a member of the NAACP [National Association for the Advancement of Colored People]. We went together to NAACP rallies and certainly participated in the civil rights movement to the extent that we were able. I'm also proud to say that my father was the hospital director when Strong Memorial Hospital [in Rochester,

NY] became integrated. So I think in my interactions with my parents, they helped me to develop sense of fairness, of equality and appreciation for each person as an individual.

AZ 4:38
How did they communicate that to you as a as a young person growing up?

JB 4:43
I think most powerfully, [they communicated] by example. They communicated this to all of our family, and what was critically important was to appreciate the value of each individual person with a sense of fairness, equality, and opportunity.

AZ 5:14
Was this sort of mindset that supported the civil rights movement from a white family like yours widely accepted or supported by other members of your community?

JB 5:27
I think that the community that I grew up in was quite supportive of the civil rights movement. But it was still a difficult topic. The segregation of schools took a long time. If you take, for example, my graduating high school class, we had 444 students and a single African American student. That was shocking. Absolutely shocking.

AZ 6:08
Was there a particular experience during the 1960s that impacted you the most?

JB 6:15
So there were a whole diversity of experiences in the 1960s that were important. We've talked about the Civil Rights Movement. Also, there was the Vietnam War. Of course, the Vietnam War led to great controversy. We had draft cards, and draft at that time was decided by lottery based on your date of birth. I had a draft card, and my birthday was drawn second. Now, of course, I was going to have an educational deferment, and Richard Nixon stopped the draft. We were quite grateful for that. In addition, I think it was the start of a movement of environmentalism. So take, for example, the issue of litter along roads, it was Lady Bird Johnson, the First Lady, President Johnson's wife, who started the Keep America Beautiful campaign. Earth Day happened in the 1960s, the first Earth Day, and I can recall as a student going to plant trees on Earth Day. There was a sense of profound idealism that believed that if something was right, that we could overcome any obstacle to make it right. So it was a positive idealism, and I think it was absolutely inspiring.

AZ 8:23
When did you start to think about health disparities with that mindset?

JB 8:30
So my father had grown up in the South, and my grandmother lived in Charles Town, not Charleston, Charlestown, West Virginia, and she had a devoted lovely African American housemaid. This unfortunate woman had type two diabetes, and she suffered terrific sequelae of her type two diabetes. [She] ultimately became blind, lost her lower extremities, and my father was always quite careful that when we went to visit my grandmother, we would go to visit Christine [the housemaid] at her house. It was critically important to appreciate the lack of resources that she had, and the lack of access to the best medical care, because certainly those complications could have been avoided. So that was an early start to the [inaudible] saying of health disparities as they existed.

AZ 10:08
How old were you when you visited Christine?

JB 10:13
I was probably 11? 12?

AZ 10:18
And did your father explain to you that her suffering from diabetes could have been prevented if she was in a different environment, or from a different background?

JB 10:32
I don't think he explained it explicitly. I think it was implicit. So my father was the kind of teacher who tended to teach through the Socratic method: not telling you answers, but asking questions, and letting you come up with answers.

AZ 10:59
What are some of those questions that he could ask you?

JB 11:07
So, he might say something such as, "we've visited Christine, you've seen some of the troubles that she's having? And how do you think that happened?"

AZ 11:37
How did you react to questions like those?

JB 11:41

I tried to be thoughtful, and based on values that my parents had shared with me, I tried to process the answer, thinking about equality, access to care, the impact of socio-economic factors on health and how profound it could be.

AZ 12:09
Sounds like you were thinking about that even much before you got to medical school. Is that right?

JB 12:14
Well, to some extent, it was so obvious, you couldn't help but reflect on those differences. The differential opportunities that people had, based on socioeconomics, race, a whole variety of of circumstances.

AZ 12:48
When you were finished with residency here, did that thinking influence your decision to stay at Duke, as opposed to working in a private practice like some of your classmates?

JB 13:04
So I came to Duke in 1981, as an intern in internal medicine. At that time, we are on call every other night. So it was quite a rigorous training system. As I rotated through different specialties, I was having a hard time choosing a specialty. Ultimately, I chose infectious diseases, because it gave me access to a whole breadth of opportunities in medicine, I could see post operative patients on the surgical service. I could see obstetrics and gynecology patients. At that time, I could see pediatric patients. So instead of making a choice that narrowed my opportunities, I felt like I was making a choice that broadened opportunities. I elected to stay here at Duke to do my infectious disease fellowship. In that context, I thought perhaps I wanted to go into private practice in Durham because there was nobody practicing infectious diseases here. So, I had tentatively agreed to join a multi-specialty group here in Durham.

AZ 14:51
How did you end up deciding not to go there?

JB 14:55
So in the context of my residency and fellowship, I had started to take care of people with what would ultimately be called AIDS. My practice asked me to delay for six months to join them, because they had taken another practice member, and their finances were a bit tight. So Duke offered me the opportunity to continue here at Duke. I had started to become involved in research focused on the care and improved treatment of people with HIV/AIDS, and I found that work to be tremendously rewarding. I was part of a research team that was interdisciplinary. We were reaching out to a population that medicine was forgetting or didn't want to take care of. The

most important reason not to go into private practice was that I saw value in what we were doing here at Duke and I had the opportunity to work with exceptional people, such as Bart Haines, David Durack, Danny Bolognesi, and Kent Weinhold. The second reason that I elected not to go into private practice is that — I went to visit their office, and we were taking a tour of the facility. In the waiting room, there were two sets of bathrooms. One of the more senior members of this practice said to me, "John, that used to be the colored bathroom, perhaps your patients can use that one." So I had some sense that private this private practice opportunity was not going to be consistent with the values that I held dear to my heart.

AZ 17:43
What did the neglect for HIV/AIDS patients look like at Duke when you were a fellow?

JB 17:53
So when I was a resident and a fellow here, we started to see increasing numbers of people who met the clinical definition of what would be called AIDS. People were afraid to take care of those patients. There wasn't an understanding of how they became so sick. Certainly, there was evidence that there was an infectious cause. But the infectious cause hadn't been discovered. Therefore, people who didn't know if the infectious cause was spread by casual contact, by taking care of patients, by taking somebody's dinner into their hospital room. As a consequence, quite a few healthcare workers and the population in general, were quite afraid. I saw patients suffer from lack of medical attention. The early days were quite hard for patients, and they suffered discrimination, stigmatization, and poor health care as a result.

AZ 19:26
What did the lack of attention look like to you when you were observing? How did you how did you notice it?

JB 19:35
So I would notice the lack of clinical attention for hospitalized patients, when you would see their meal tray just laid outside the room and nobody would take it into the room. I witnessed it in making refer roles to faculty, medical colleagues, who would not want to take care of a patient who had what would ultimately be called AIDS. As a consequence, I developed a list of referring physicians who could offer specific services, who I could call upon for assistance. This was true across multiple specialties — but take, for example, surgery. I had a couple of surgeons, such as Dirk Iglehart, who I could call upon to take care of patients and they did so without hesitation. I was so grateful to those colleagues, who recognized the needs of patients and were willing to provide care.

AZ 21:11

For the providers, not only faculty members, but also other staff in the hospital, for those that pushed back on providing care to your patients, the ones that held that stigma of the disease in their mind and refused to give care, did you ever push back on that mindset that they had?

JB 21:31
So I tried hard to educate colleagues, and to reassure them by personal example and through personal commitment. But sometimes, there were people who were quite refractory to that education and simply didn't want to take care of patients. Now, that's a terrible circumstance for a patient: you want a patient to go to a provider who has a commitment to take care of that person. So that's why having that portfolio of providers to assist with patient care was critically important. I certainly had great frustrations. My secretary could tell when I was quite frustrated because I have had a pension for slamming the telephone down and breaking telephones. There was a wonderful communications officer Bobby Clemens, who knew that when Kathy called him to come to John's office, it was to bring a new telephone for [John].

But I think also it is critically important to demonstrate to my colleagues, that if they took care of a patient and an accident happened — this happened one time in the operating room, where my surgical colleague had a needle stick when he was operating on a patient. I personally went to the Duke pharmacy and picked up AZT [azidothymidine, the first antiretroviral medication for HIV/AIDS], and took it to the operating room so that he could get started on post exposure prophylaxis immediately. That is teamwork. And that's what was critically important to take care of a patient population that faced obstacles in accessing appropriate care.

AZ 23:55
Did that surgeon continue to work with you after that accident?

JB 23:59
Absolutely. He took AZT, which at the time was the only approved drug. He took it for six weeks, he stayed HIV negative, and he has been my good friend to this day.

AZ 24:22
How did this stigmatization slowly change over time? How did that happen?

JB 24:35
So the stigma associated with HIV/AIDS was quite severe at first, and I think it's because HIV was a sexually transmitted disease. At first, of course, it was in men who had sex with men. Subsequently, we started to see it in the context of heterosexual contact, then we saw mother to child transmission, then we saw people who inject drugs and acquire HIV. Now, for each of those groups, those behaviors can have significant stigma associated with. To this day, the stigma has decreased some, but it is still ubiquitous around the world. I think a critically

important factor in decreasing the stigma is having personal contact with somebody who you know, who has HIV. It's that personal contact that changes things.

I can recall one of our clinic spaces, was on Howland Ward. This particular word was divided into our clinic and the secretarial pool, because in those days, we used to dictate notes, and the secretarial pool would type them up to be put in the paper chart. Well, the secretarial pool was terrified that they were going to interact with our patients. They didn't want to open the door after it's been touched by somebody with HIV. Well, after six months of personal contact with our patients, they were totally charmed. They were baking cookies for our patients and knew them by name. They had a close and affectionate relationship.

AZ 27:06
What did you tell those secretarial workers at first when they were upset?

JB 27:14
We focused on education. By that point, there was an established literature through the CDC and other groups that had looked at nonsexual household contacts and health care workers. They found no transmission, outside of the context of a sexual relationship. So, we educated them with those fact I think that helped, but it was still the personal contact, the fact that our patients would come in and say, "Good morning, how are you today?" Many of our patients were quite charming, and so their relationship grew and it broke down barriers.

AZ 28:15
Did they eventually express regret for the attitude that they held at the start?

JB 28:25
Regret is perhaps too strong a word. I think they felt enlightened and relieved. I don't think that they expressed remorse, per se. But I think they felt that they had been enriched by getting to know these patients. Then, of course, there were famous people like Rock Hudson, who came out with HIV infection. Then it was Magic Johnson. Magic Johnson, you know, was a hero to many, many people, especially in the African American community. He was a powerful and humble spokesperson on behalf of people living with HIV. He came back to play the NBA after his diagnosis, which of course, was quite controversial. He came here to Duke, we had him speak at the Carolina theatre to the community, and in particular, to the African American community. We had the opportunity to spend time with Mr. Johnson and he was a profoundly humble man. He had family in eastern North Carolina, and so he understood the issues of sexually transmitted diseases, poverty, and access to care in the rural south. So he [Magic Johnson] was quite insightful and wonderful.

AZ 30:26

Do you think the story of the secretarial workers and the patients in the Holland Ward represents a pattern of greater greater acceptance through exposure and education in the health system as a whole? Or was it limited to that specific case?

JB 30:47
There is no question that that personal contact and relationships is absolutely essential. I have seen this happen time and time and time again, where some of the stigma, some of the obstacles in interpersonal relationships can be overcome, when you have that personal contact and relationship.

AZ 31:24
Where there are cases when people have persisted and things still fail to change.

JB 31:32
There were some people who were quite reluctant to change. I can recall, when my children were young, there were some parents who didn't want my children playing with their children. I can recall, I had a patient who had a gastrointestinal bleed, and we didn't have beds in Duke Hospital. He had to be hospitalized in western North Carolina, at his local hospital. I talked to the treating physician on the phone, who was just screaming at me, and said, "How can I make him take care of those patients?" I told him very openly, exactly what to do. I reassured him, and he just carried on and said, "I going to send my wife and children out of town." He was just hysterical.

AZ 32:47
Was that common?

JB 32:50
I wouldn't say it was common, but it certainly happened from time to time.

AZ 32:56
And it continued to happen even when more literature started to come out about how HIV was transmitted?

JB 33:04
It did, it did continue. Now, in historical context, I have to point out that for an individual practitioner in a rural area, she or he is not going to have experience with people with HIV, [he/she] is not going to have that knowledge about treatment, and wouldn't have a whole team of personnel to help take care of the patients. We had a fantastic team here at Duke that included other health care practitioners, nurse practitioners, physician's assistants, a pharmacist, multiple social workers devoted to the care of patients, and an outstanding group of nurses. If you're in a

small practice, you don't have access to all those services. As a consequence, many patients came to our clinic because of the diversity of services that we can offer to them.

AZ 34:27
By a diversity of services, you mean, what kinds of other things?

JB 34:32
So, expert medical care, access to clinical trials, a pharmacist, nursing staff who were supportive and took good care of patients. Social Work support was absolutely critical, because most of our patients were poor. Many of them had been ostracized by their families. Many of them that may have had a prior history of incarceration. There were quite complex social problems that our patients were facing, and having an expert group of social workers help to address those problems... we actually got to the point where the first person, the first professional, that a patient would see in our clinic would be the social worker, because understanding the psychosocial and economic context of an individual patient was critical as you designed a health care plan.

AZ 35:50
How did you work with the social workers in your clinic?

JB 35:55
We met weekly with the social workers to discuss individual patients who were having problems. We also had a weekly group therapy session. So there was a psychiatrist on the faculty who donated his time to essentially run a support group for those of us who worked in the clinic, so we had ample opportunity in this inter-disciplinary group to exchange ideas, to talk about problems, to talk about mutual support for each other. It was an outstanding example of how multidisciplinary healthcare teams can be high functioning and patient centered. It was a harbinger of what healthcare was going to become.

AZ 37:08
What kinds of things would you discuss in group therapy with the psychiatrist?

JB 37:17
In group therapy, we certainly would discuss loss, we would discuss coping skills, we would discuss how we related to people outside of the clinic. I think it was critically important because it gave us an opportunity to exchange ideas to support each other, and identify ways that we could keep our focus on the patient.

AZ 38:09
Could you tell me about one memorable time when you needed support from that group?

JB 38:19
At that particular time, the median survival after a diagnosis of AIDS was 24 weeks. So that's six months. Each year, over 25% of our patients died. That is a massive number of patients to lose in in each calendar year. My peers, the people on the team helped to support me and helped me to appreciate the wisdom that our patients shared with us. They helped me to understand that it was a privilege to know someone in the last six months of their life, because if you want to know what's important, people with six months to live are thinking about those issues and communicating to you what the crucial aspects of satisfaction, happiness, and, ultimately, their demise [are]. What's really important is what they shared with us.

My colleagues helped me to appreciate that, my colleagues helped me to reach out to people, and we came to recognize the importance of keeping people in their home environment. Patients were quite afraid of coming into the hospital, because they lost control, they couldn't be sure they were going to have their pain taken care of, sometimes their significant others couldn't come and visit them, because there was no such thing as same sex marriage: family members might kick out a partner who had been with them for years. As we listen to our patients, they wanted to stay at home, my colleagues helped to inspire me to make home visits, to make house calls, to pronounce people dead at home, and ultimately, to attend the funerals of some of my patients. The practice of medicine wasn't just prescribing pills, it became understanding the full environment of a patient and understanding their history, what their home life was like, and then, of course, the ritual of a funeral. That helped to make my career much more satisfying. We wish that for all health care providers.

AZ 42:11
What made home care such a challenging thing to implement for these patients?

JB 42:18
There were a number of obstacles to having people stay at home as opposed to coming in the hospital. The first issue was the issue of having a significant other in the household, who could take care of them. Some of our patients were ostracized by their families. Some had lost a partner to HIV/AIDS. So we worked with the community to have what was in essence, a buddy system. Churches in Durham were quite active in helping to keep people company, to bring meals to patients. We had quite a few discussions with hospice at that time. The hospice model was such that, at that time, and it's changed since then, but at that time, the hospice model was entirely focused on palliative care and no active interventions. We had patients who had for example, CMV retinitis, and CMV retinitis, if it's not treated, lead to blindness. The only way to preserve sight in those patients was to get the intravenous medication that was incompatible with the hospice model. But sight is critical to quality of life! It took time for us to be able to engage hospice, they wouldn't get involved in the beginning, and we had to identify alternative systems to support patients at home.

Another obstacle to having patients die at home were funeral homes, because funeral homes didn't want to take people with AIDS. At that time, Duke Hospital had a crematorium. It was the least expensive place — this is shocking — the least expensive place to get cremated in the city of Durham. So, when patients died at home, I would get a call from the caregiver to come and pronounce the patient dead, which is what I would do. I would call the medical examiner to notify the medical examiner. Then, I had a pickup truck, and I would help the caregiver to put the deceased person's body in the back of my truck and bring them here to Duke to the crematorium. I did this quite a few times. There was a time I had a particularly tall patient, and we sat him kitty corner in the back of the truck, but he was still too tall. We had him wrapped in a sheet, and his feet stuck up over the tailgate, and I was absolutely sure the Durham police were going to me pull over on my way to the hospital. But fortunately it didn't happen.

AZ 46:34
I find it really interesting that the churches helped out a little bit during this time to provide for these patients at home because many at that time had homosexual relationships, and I wonder if the churches would have been disapproving of that just like many other people in the community were. But how come you think they were still willing to help out so much?

JB 47:16
There were certainly churches, who had negative feelings, and stigmatized people with HIV/AIDS. But individual church members, in the Christian spirit, saw each person as a child of God, and in their Christian spirit, they would help to take care of those people who were at home, dying. It included multiple denominations, it included African American churches, and individual Christians stepped up and practiced their faith, which was wonderful and inspiring.

AZ 48:20
I see. Did the social aspects of your patients lives ever change the way that you medically treated them?

JB 48:41
That is an interesting question. Yes, understanding the social context of their lives helped me to be a much better doctor. I became involved in quite a few community activities. There was a local group, the Gay Men's Health Group, who sponsored a chef's night, and I was invited to be a celebrity chef. I had a wonderful time cooking and my gay colleagues had a wonderful time enjoying the food that I had cooked. A number of times, I went to the homeless shelter to see some patients who were injection drug users. I used to volunteer as a physician at the Durham County Health Department, which there's this old Durham County Health Department, which was a brick building across from our church, St. Philip's church, right next to the bus station. I used to volunteer to go out there to take care of patients, and it was quite common for prostitutes

to hang out on the corner there. I would either be walking into church or walking into the health department. And I'd hear, "Hey, Dr. Bartlett!" And all the prostitutes were waving at me. It was so funny.

AZ 50:49
Why do you think you were one of the only physicians that cared about the public, uninsured patients in infectious diseases?

JB 51:05
So the historical context of medical care at Duke is that there was a two tiered system. There was a system for patients who had insurance, and they went through what was called the private diagnostic clinic. For patients who didn't have insurance, there was a sliding scale clinic that all patients could access in that sliding scale payment system that was largely staffed by trainees who were supervised by faculty. As the HIV epidemic in the south started to change, it evolved from concern amongst men who had sex with men (MSM) who were employed and had insurance into MSMs who might not be employed and have insurance into injection drug users into commercial sex workers, et cetera. As a consequence, there was a growing need to have access for uninsured and under resourced people to come to clinic.

That's when I helped to start the public infectious diseases clinic for those patients to have access to care. And our clinic staff were fantastic, supportive, and that clinic just grew and grew. Now, over time, the Duke system has changed. And of course, all patients now have access to the same quality of care. Duke has a charity care system, such that patients without insurance and without resources, can have access to the services we offer at Duke. I'm proud to say that in all the time of the Duke infectious diseases clinic, we have not turned away anyone for lack of resources. That was something we insisted upon, and we have had fantastic support from the Duke School of Medicine and the Duke hospital administration to ensure that we can take care of all people in need.

AZ 53:58
In those early days, was the care for HIV patients in the public clinic different from the ones in the PDC [Private Diagnostic Clinic].

JB 54:11
I think the care was quite equivalent. Ultimately, I became the most experienced HIV provider. So you could speculate that experience was a primary determinant of quality of care. Ultimately, perhaps we exceeded the level of care in other parts of the clinic system.

AZ 54:44

What do you think were some of the biggest challenges that you and your team faced when setting up that public clinic?

JB 54:51
It was clear to us, as we set up the public clinic, that it was critically important to have an interdisciplinary team. I am not a social worker. I have no clue how to mobilize Medicaid for a patient. I have no clue how to deal with homelessness. I have no clue how to efficiently refer someone for substance use disorder. So it was critically important to have an interdisciplinary team. We were quite fortunate that Dr. Joseph Greenfield, who was Chair of Medicine at that time, appreciated the fact that if we put together a highly effective, interdisciplinary team to focus on outpatient management of patients, it would keep the inpatient census low. That made hospital administration happy, it made our patients happy, and Dr. Greenfield was a powerful advocate in support of that approach. He contacted hospital administration, and hospital administration from Dr. Bill Fulkerson, Mr. Kevin Sowers, they were totally supportive and helped to invest in our clinic staff, so that we had the staff needed to achieve that goal.

[BREAK]

AZ 56:53
Can you tell me about how you assembled the team of people who supported you in that clinic?

JB 57:01
The assembly of the team, was a bit random and haphazard. When I first joined the team, we had a nurse, Tony Adinolfi, who was hired to perform clinical trials. Ultimately, he became the clinic nurse manager. We had a phlebotomist who drew our patients blood name Barlett Humphries. Barlett really was a remarkable person. Not only was she quite skilled at drawing blood, but she was an intuitive psychologist. She knew exactly how to build a rapport with patients and support patients, and was truly a remarkable person. Then Ken Shipp came as a pharmacist. He was quite knowledgeable about all things pharmaceutical, and was kind, supportive and instructed our patients on taking their medications. Then, the woman who would ultimately become my wife came as a social worker. She was hired on grant, and it come from Durham County Hospital, as it was called at that time. So, piece by piece, we assembled a skilled team of people to take care of our patients. I wish I could say that when we started, I had it all in my head, and we were going to hire each of these categories of people. But it was a bit more haphazard. It worked out incredibly well, because the same kindness, altruism and professionalism was present in each member.

AZ 59:34

Did these members find your clinic because they were interested in working with patients like yours? Or did you have to go out and look for people who played those roles and could have those skills?

JB 59:49
So I think what was critically important was the motivation to take care of people in need. Here, we had a group of patients who were historically stigmatized: men who have sex with men, bisexual men, people who inject drugs, commercial sex workers, et cetera. In the healthcare system, they were largely at forlorn and forgotten. So we were looking for people to take care of that population, whose motivation was to meet a critical need. I think all of us on the team had the same feeling, that this was an opportunity to care for a patient population, who otherwise wouldn't have had care. In that way, we could truly make a difference. So, for a variety of motivations, be they spiritual, or human altruism, we all came together to take care of those patients.

AZ 1:01:30
As you know, I'm also interviewing your wife later, and then next week of interviewing Julia Giner, another one of the nurses who worked with you. Can you just tell me a bit about how your professional relationships with them developed?

JB 1:01:47
So I first met Julia, when she was a nurse in the hospital on 8100. She was a fantastic nurse, took wonderful care of our patients, and had a strong connection to advocacy for the communities who were at risk. She came to join us in clinic, and I had that prior relationship with her in the context of patient care in the hospital. When Patricia [my future wife] first came to work with us, she had experience in providing social work care, to people with HIV/AIDS at Durham Regional Hospital. She also, as someone who is quite involved with the performing arts community, had quite a few friends and performing colleagues who were men who had sex with men. So she was quite tied to that community. In addition, she was the founding chair of the board of an organization called the AIDS community residents association, or ACRA, as it was known. That organization focused on housing for people who who otherwise would be unhoused because they were ostracized by their families, didn't have significant resources, or just didn't have any place to go. They raised funds and purchased a house where people living with HIV could stay safely and be cared for.

AZ 1:04:07
Were there any particularly memorable moments when you saw them or any other members of your team doing very important work at the time?

JB 1:04:17

So with Julia, you know, we shared, come and motivation to take care of people in need. Julia ultimately came with us to Tanzania and helped us to grow the research program at the Kilimanjaro Christian Medical Center. She was our next door neighbor, so our bond was quite tight, and we were close friends, my wife, Patricia, myself, and Julia. We had great professional respect for each other. For Patricia and myself, it was pretty clear that we were kindred spirits and soulmates. We had the same belief system and the same idealism. She is perhaps a bit more fearless than I am. She can be more outspoken than I am, but we shared so much in common, that ultimately, we developed a very close personal relationship, and have been married for the past close to 32 years.

AZ 1:05:53
What do you mean when you say that she's more fearless than you are?

JB 1:05:56
So, Patricia is not one to acquiesce to conformity. I, in my academic career, have to follow certain behavioral expectations. That's not to say that she misbehaves, but she can be quite outspoken and express her views in situations where I might be a bit more reserved because of expectations. For myself.

AZ 1:06:56
Is there a specific example you can give of that?

JB 1:07:01
So we're both quite involved with advocacy in terms of HIV testing in the state. Both of us testified a number of times before the North Carolina General Assembly with regard to testing and reporting issues. Her testimony was was perhaps more powerful than my testimony, because she had a certain righteous indignation, that was well founded. She helped to inspire me in taking difficult stances. So there was an occasion when the North Carolina Department of Health wanted to come to our clinic and examine the records of our patients to make sure that all patients had been reported to the state. The state officials came, and I asked them to stay in the waiting room and told him that I would not allow them to see the records of our patients. That was private, protected health information. I said, "No, you may not do this." And fortunately, Kate Sigmon, who at the time was one of the hospital attorneys, quickly came out and to join me, and we were able to successfully tell the state that they could not see the records, and could they please depart?

AZ 1:09:11
Why did they want to see the records?

JB 1:09:13

It was a complicated political situation in which it was felt that if the state had the names of all people who are HIV infected, all hospital workers in the state could be notified so that they would protect themselves. It was around the time when we were coming to the conclusion of universal precautions that we should consider all patients as potentially infectious. Prior to that, people didn't wear gloves drawing blood and those kinds of universal precautions weren't in place. Politicians in our state felt that if they had the names of the people with HIV and the names were available to all health care workers, that the health care workers could take steps to protect themselves. This was very poor public health policy being driven by politics. It just so happened that a conservative candidate for governor at that time, his daughter was a nurse. He was advocating out of his love for his daughter, so his daughter could protect herself. But it was politics misguided. The correct public health policy is — you can't look at someone and say: I have hepatitis B, I have hepatits C, I have HIV, I have whatever — you have to make the assumption and take the responsibility to protect yourself.

AZ 1:11:20
Which year was this happening in?

JB 1:11:23
It was approximately 1988? 1989. Somewhere around in there.

AZ 1:11:39
Yeah, because I wanted to ask, you were setting up this clinic in the early 80s, so before that time. I know that the 80s was a time of general conservatism in the United States. How did that political environment affect your work?

JB 1:11:59
So when AIDS was first described, Ronald Reagan was president. It took him many, many years before he would ever even utter the word AIDS. His Vice President, Vice President Bush, came to the International AIDS Conference, and was booed off the stage. We had such powerful advocacy groups, such as ACT UP and Gay Men's Health Crisis, who did fantastic things to advocate for improved treatment for HIV infection. Our conferences were very colorful, and never boring. I can recall, I was giving a talk at one of the international conferences in Geneva, Switzerland, and all of a sudden I heard the the bull horns were were starting. What that meant is the activists were coming, and they completely disrupted my talk. My talk was being given, what was at that time, the Glaxo welcome exhibit. I had to step aside, and they completely demolished the Glaxo wellcome exhibit. Of course, I was perfectly safe, and I was quite entertained to see this happen.

So, there were some amazing things that were happening, but you have to put it in the context of advocacy for a population of people who were watching each other die, one by one, by one, losing friend, after friend after friend. Imagine how that would make you feel and imagine the intense anger, when there were people who weren't talking about AIDS because of stigma, when there wasn't a mobilization of resources to identify new treatments, when the arcane rules of the FDA prevented access to new treatments. The activists took the situation into their own hands and changed the rules. It now has set a precedent for many other diseases. I have many friends who were part of that advocacy movement. They were courageous and powerful people.

AZ 1:15:16
How did it feel to be speaking for them, and also working alongside them, this community? Whether it was the LGBTQ community, or like you said, the professional sex workers, or the drug users? How did it feel to be speaking for them, when you yourself are not exactly part of that community?

JB 1:15:42
So I was proud to be his speaking on their behalf. Because, as I said before, they're all God's children, and I have a deep respect for all of humanity. I was pleased and proud to represent my people.

AZ 1:16:12
Were they always happy to have you be their representative?

JB 1:16:15
Oh, I'm sure they weren't always happy. I certainly felt to be an esteemed member of each of those communities, and I think I was respected. I sincerely appreciated that.

AZ 1:16:45
Why do you think HIV AIDS as an infectious disease is perceived so differently, and stigmatized so much more, compared to other infectious diseases which are also contagious?

JB 1:17:04
It is absolutely about sex. Absolutely about sex and other behaviors such as sharing needles. But you know, of course, we had seen this same thing with other sexually transmitted diseases, such as syphilis, gonorrhea, and chlamydia, but there were antibiotics for those, and so they were reversible. HIV is not reversible. It's treatable, but it's not curable.

AZ 1:17:47
How do you see the clinical research that you were involved in intersecting with your activism work as a physician?

JB 1:18:04

To be a clinical researcher working on HIV had great joys and deep sorrows. The greatest joy was seeing the advent of triple antiretroviral treatment and how that led to a transformation in the disease. All the sudden people's viral loads became fully suppressed. All of a sudden people became healthy. It was a Lazarus syndrome. They came back to life. I mentioned earlier, up until 1995, at least a quarter of our patient population died every year. The next year, after triple combination therapy, that number fell to 8% and has continued to go down since then. So, to witness that profound impact on the course of a disease was truly a privilege, and then to be able to transition to our work in Africa and see it happen again, is a double privilege.

AZ 1:19:38
Did you encounter any obstacles along the way during those early clinical trials for the therapies for these patients?

JB 1:19:50
So in the early days, a definitive clinical trial had to have a placebo control. You would have randomized two groups of people, comparing drug X to placebo. That scientific rigor, you had to have that kind of clinical trial design. But it was difficult and we're all supposed to be double blind, so you didn't have the burden of knowing who was on placebo. And as it turned out in particular with AZT, AZT changes the size of red blood cells and makes them larger. So you could see in some patients that their red blood cells grew and others it didn't. Well, the patients figured that out really quickly. In the phase II B trial of AZT, we had quite a few patients in this study. They would have a party in which they put a bowl into the middle of the table, and each person would take their capsules, because they could come apart easily. They were those two piece capsules, and they put all the powder into the bowl. They had aliquots of medication that they would distribute to each other so that they could be guaranteed that every person had access to some AZT. You ask yourself, what does that do to the scientific rigor of a study? Well, if anything, it tends to decrease the difference between the two groups, yet still, AZT demonstrated efficacy in terms of survival. Despite the fact that there was some sharing of medications. We also had some patients who were chemical engineers, and they would discern whether they were getting an active medication or placebo, by checking the melting point. Then they could unblind themselves as as to which medication they were getting.

AZ 1:22:43
How did you find out about these flaws in the clinical trials?

JB 1:22:50
People told us?

AZ 1:22:52
And what was your reaction to that?

JB 1:22:56
Mixed. You know, of course, you had to know that it was compromising the scientific rigor of the study. But people were desperate. I mean, I can't tell you how many times I had the partner of a dying person carry, carry his dying partner into the waiting room of the clinic. You know, I understand why they did what they did. They were scared. They were dying.

AZ 1:23:50
Okay, I have just one last question for you. At the very start, I think you call yourself an idealist for what you believed in as a doctor. How do you think being an idealist relates to how you're an activist for these people?

JB 1:24:11
So, yes, I am an idealist. It permeates my entire life. And we started this interview by talking about my parents. My parents helped me to be an idealist. The team I work with helped me to be an idealist. My mentors helped me to be an idealist. My wife helped me to be idealist. And if you're an idealist, it is all encompassing. It doesn't just stop with writing prescriptions. You have to be involved. You have have to roll up your sleeves and become an activist. It's absolutely essential.

AZ 1:25:13
Okay, that's the questions that I had for you. Is there anything else that you wanted to share with us before we finish off?

JB 1:25:29
So I would come back to something that I think is quite important, and I think you've heard me mention multiple people who are mentors to me, and help to inspire me here at Duke. I think that something that is quite positive about Duke, and that, despite the fact that we were a traditional Southern institution, there were people who shared the idealism, and helped to inspire and mentor me. In addition to the ones I previously mentioned, Dean Klotman, Mary Klotman, was just an incredible mentor to me. I'm so grateful for her support over these years. I think mentorship beget good mentorship begets good mentorship. That's an important concept. Some of the models of care that mentors, myself, the team, put together have created a system of patient centered care delivery, that is now being replicated in many other clinics and many other chronic disease states. That is important because it was nurtured, fostered, and grew here at Duke, and Duke should be proud of that.

AZ 1:27:40
All right. Before we stopped the recording, I'm going to get 15 seconds of just like silent room to room tone. And then also, after that, would you be able to just like briefly introduce yourself and

their production style again. So if I if I were to do that, it would sound like my name is Anthony Zhao. And I'm a second-year undergrad at Duke University, but your version of that? Sure. Okay. We'll have to wait for 15 seconds.

JB 1:28:27
My name is John Bartlett. I am a professor of medicine, global health and nursing. I have had the privilege of working at Duke for almost 43 years. It has been a remarkable journey, and I'm incredibly grateful.