1. Henrietta Lacks and the Baltimore Community

Exclusionary practices have shaped how vulnerable populations understand their agency in the research process [1]. One narrative has been particularly powerful for the Baltimore community—the contributions of Henrietta Lacks. Mrs. Lacks was a 31-year-old patient at Johns Hopkins receiving treatment for cervical cancer. During the biopsy, her cells were sent to a research lab without her knowledge and cultured to become the first human cell line [2].

2. Methods

Semi-structured interviews focused on what brought Hopkins affiliates and community members to the work they do and their understanding/identification with the concept of “lay scientists.” Participant-observation sessions primarily occurred at the Day at the Market, a bimonthly event run by Hopkins that provides health resources to the Baltimore community at the Northeast Market.

3. Results

The “lay scientist” is defined as an individual who is investigating a topic of interest but not a professional researcher with specific training/credentials [4]. When speaking with various community members, their unique relationships with these concepts highlighted the diverse roles encompassed by this definition. Ms. Barbara Bates-Hopkins, one of the lead figures at the Day of the Market spoke of her role:

“We’re these live connectors.”

Another community health advocate, also affiliated with Hopkins described the impact of her childhood in her journey as a lay scientist:

“I was raised to participate in the community.”

4. Discussion & Future Directions

Individuals appear to enter these roles through a variety of mechanisms, but two stand out in particular. Patients’ experiences can inspire greater interest in understanding their disease. Furthermore, programming such as the Henrietta Lacks Memorial Lecture educates the community about their rights in research. Attendees have expressed interest in shaping research, for instance, by serving as a non-affiliate member of the IRB.

5. References

4. Lee Bone 2018 Interview by Anagha Prasanna.

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