Why an understanding of anthropology is important for cancer control

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Anthropology has a key role to play in implementing cancer control programmes in low- and middle-income countries through uncovering the local realities and real-life experiences behind those suffering with cancer to create more appropriate strategies to beat the disease. As the article shows, interviewing techniques can be all important in finding out the truth.

Anthropology is a social science using a wide range of social science research methods to understand the ways in which people live in different social, cultural and political settings and how they perceive the world around them. Contrary to other social science disciplines, it is based on a commitment to long-term empirical research in local settings.

The rising incidence of cancer that many low- and middle-income countries are facing today is raising substantial social, political, technological and economic challenges. Low-quality primary healthcare means that people are more likely to be diagnosed with advanced disease. While receiving treatment, poor patients often have to live outdoors because they cannot afford accommodation. Lack of regulation and accountability and a rapidly expanding private healthcare industry facilitate the over-use of diagnostic and therapeutic interventions. These and other challenges require research that goes beyond the traditional biomedical-clinical nexus.

Implementing adequate cancer control programmes in low- and middle-income countries without understanding the conditions on the ground is a recipe for failure. What we urgently need today are systematic studies of local realities and real-life experiences that create opportunities to empower change and improve cancer control. Equally urgent is a collaborative form of research that can elicit the patient's voice and that can provide us with the necessary means to understand it. This means that we need to put the emphasis on structures and strategies rather than relying on a reductionist model of individual behaviour that often blames people for their illness.

Because of its emphasis on local conditions, anthropology can provide us with a better understanding of how oncology can be practiced in a radically different setting, often marked by diversity, complexity and massive therapeutic disparity. Anthropology can also help us move beyond research and policy agendas that are frequently driven by the concerns and priorities of high-income countries.

Talking about cancer

Cancer is a topic that many prefer to avoid. The disease is often surrounded by silence. This makes it a challenging subject for social science research. How to study a disease that is frequently denied, repressed and concealed? As part of a research collaboration with Tata Memorial Hospital in Mumbai, India we conducted semi-structured interviews with 400 patients and family members. In these interviews, we asked open-ended questions focused on the accessibility and affordability of cancer care in India. All interviews were conducted in Tata Memorial Hospital between October 2017 and April 2018. For the research, we received approval from the Institutional Ethics Committees of Tata Memorial Hospital, in addition to approval by the Indian Council of Medical Research of the Government of India. The interviews were conducted in Hindi, Bengali, Marathi and English, depending on the preferred language of participants.

To showcase anthropological research and highlight some of the challenges of knowing cancer, this article presents an excerpt from an interview with a farmer from Maharashtra. In this interview, we asked whether there had been other cases of cancer in the family, neighbourhood or village.

Q: Did you ever hear the name of cancer? Or did anyone have it in your house?

A: No, never heard it.

Q: Did you ever hear the name?

A: No, never. First time.

Same interview with the same person after 20 minutes and questions about other topics.

Q: And [has] this kind of big disease [cancer] [occurred] anywhere in your family or village?
A: No.
Q: What is the kind of perception about this disease in your village?
A: In my village, this disease hasn't happened to anyone. Not to anyone as yet.

After 30 minutes and questions about other topics.

Q: You have been here for so many days. You know it's a cancer hospital; do you ever get scared if you get a pain in your body?
A: Yes. Earlier I used to feel so. In the beginning, when I came, I used to feel so. It's a cancer hospital. There was a man from my village who brought his son here. He also had cancer. Of the bone. Everything was good for them. They were here for one and a half years. Recently, they returned to the village. They had all kinds of facilities here. It was a child. They were given all facilities. Now they have left. They said it's good. You don't have to take any tension.

After 35 minutes and other questions about other topics.

Q: Did you hear the name cancer before?
A: Yes. cancer, I had heard the name. My uncle had cancer. He died.
Q: Your real uncle?
A: Yes.
Q: What kind of disease?
A: It was here, in the mouth.
Q: He must have been eating tobacco.
A: He ate tobacco and he also drank alcohol. We took him to Aurangabad. They burnt it [radiation]. Then, we brought him to our village. For 2–4 days, he was fine. Later, he thought that his disease is fine now. He started drinking again. He died.

How did we get to know what we wanted to know? By starting a conversation and letting the person speak until we got the whole story. As anthropologists know, an initial response to a question often gets revised in the course of a conversation. This raises the following question: Can we know something about understandings of and experiences with cancer if we don't give people enough time and space to express themselves? How robust and reliable are cancer awareness studies really, especially when they are based on surveys?

Anthropologists place methodological emphasis on observation, indirect questioning and redundancy (asking the same question in different ways again and again). Observation, indirect questioning, and redundancy can produce more robust and reliable evidence. This is important because the first response to a question is often not the most accurate one. The truth is not on the surface.

Because of its complex mode of existence in people's lives, cancer is particularly difficult to study from a social science perspective. Information can frequently be arrived at only indirectly. Accordingly, the most suitable combination of methods promising the most robust and reliable data is a mixed methods approach that includes open-ended questions. Only a mixed methods approach is able to reveal the risk of incomplete and sometimes misleading information emerging from survey data.

Conclusion

Given the rising incidence of cancer and the lack of adequate treatment and prevention, we need high-quality social science research to build a reliable and robust evidence base for cancer control programmes in low- and middle-income countries. We need approaches that go beyond the surface, that take into account the silences around the disease, and that can humanize and add richness to our understanding of cancer in heterogeneous and complex settings. There is an urgent need for empirically grounded, high-quality social science research in settings where social, political and economic forces are major causes of poor treatment outcomes. Cancer control programmes in low- and middle-income countries must be based on a robust and reliable understanding of local realities and lived experiences. Everything else is a recipe for failure. ■

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