

# Human Subjects Research and the Ethics of Intervention: Life, Death, and Radical Geography in Practice

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This is the story of our failure to save the life of a malnourished baby girl during fieldwork in 2008 in rural Rajasthan.<sup>1</sup>

## 25 June

We saw Suman lying on a cot while conducting interviews in a poor, ex-untouchable caste neighborhood in Bukhasar village. Suman appeared acutely malnourished and in need of immediate medical attention to survive. We asked her mother to take her to the hospital. A female neighbor said: "They don't have money for bus fare!" We instantly offered our vehicle but the young mother refused, saying that she could not go without her husband's permission and he was out grazing goats. We agreed that we would return to take the whole family to the hospital in a few hours. During lunch at an upper caste family's house, the male head of household explained that Suman was possessed by a "ghost in the body" and nothing could be done. Others present were aware but apathetic towards Suman's condition.

When we returned to Suman's house, we saw goats tied in the courtyard. Suman was nowhere in sight. From the courtyard entryway, we asked Suman's mother if she was ready to go to the hospital now. In response, she shot us a hostile glare, veiled her face, and ignored us. Neighbors watched the scene over their mud walls as we urged her to accompany us.

Seeing no other family member, we went to the neighbor who had mentioned a lack of bus fare. We asked her, "Why won't she come with us? Did something happen while we were gone?" The neighbor replied, "This is how it is here. You people must go now..." Perplexed with these abrupt developments, we approached the driver of our hired vehicle, an insightful young man from a distant village. We thought that he might convince Suman's father to allow us to take them to the hospital. To our surprise, he urged us against any further intervention. Heeding local advice over our incomplete outsiders' perspective, we left the village confused and frustrated.

## **26 June**

Now back in town, Kathleen phoned a Government of Rajasthan Child Development (CD) officer, Mr Verma, whom she had known for several years. She requested his help for Suman. He assured us that he would contact the CD officer responsible for Bukhasar village, who would arrange for Suman's immediate hospitalization. We believed him and put our worries to rest.

## **28 June**

We called Mr Verma and asked about Suman's condition. His reply was vague. We decided to call the Bukhasar CD officer ourselves.

## **29 June–15 July**

Mr Verma ignored our calls asking for the Bukhasar CD officer's phone number. From then on, our efforts to contact the correct officer ran parallel to our fieldwork. We made at least 50 phone calls to other CD officers in the district, visited the district commissioner's office for information, and solicited support from friends and NGO fieldworkers.

During the 15 days that it took us to connect with the officer responsible for Bukhasar, Suman's condition wrung our emotions and disrupted our thoughts. Would she survive? When would a medical team reach her? We erupted in exasperation and discussed the possibility of forcibly taking her to the hospital. With Suman on our minds, village children's poor health surged to our attention wherever we visited.

## **15 July**

Finally, Richa spoke to the correct CD officer, Mr Mishra. She provided all the details and, to hurry him along, threatened him with legal action if medical assistance was delayed any further. He assured her that a medical team would be immediately dispatched to Bukhasar.

## **22 July**

We finished our fieldwork. Assured of Suman's medical care by the correct officer, we left for our respective homes in India.

## **29 July**

Anxious to know about Suman's health, Richa phoned the family in Bukhasar who had hosted us for lunch. They informed us that they had not seen or heard any medical team but that Suman's mother herself took her to the hospital around 20 July. She was too late. Suman died on 23 July. We realized then that the mother too wanted Suman to live, and that she too had failed.

Richa immediately phoned Mr Mishra. He claimed that he had personally met Suman's mother the week before at the hospital. He could not meet the baby himself, he said without explanation, but was told by her mother that she was in

perfect health now. "There's nothing to worry about now", he repeated throughout the conversation. Richa responded by shouting "You are lying. The baby is dead, and we know!" He stuttered, "How? . . . No one informed me!" Richa grilled him about why the medical team never reached the village, but he had no answer.

## 5 August

Kathleen wrote a strongly worded letter to the District Collector, the highest government official in the district. She described our experiences and charged the responsible CD officer and his staff with dereliction of duty, lack of sensitivity, and failure to respond despite all necessary information.

We knew that a certain authority had to be mobilized to save Suman's life, but we chose the wrong authority. We activated the "proper channels" with the hope that government intervention could do what we, community outsiders, could not, but no one did anything besides make promises, avoid, and lie until the very end. We left India, beaten by bureaucracy.

## August 2008–present

We continue to ask ourselves, "What more could we have done to save Suman's life?" In an era of postmodern, postcolonial, and supposedly power-neutralizing research practices, we wonder if we took our limitations as outsiders and our research ethics so seriously that we became complicit in Suman's death. For a researcher to presume that "outsider's judgment" is better than the local community's is conceited, arrogant, and neocolonial. But we would welcome these criticisms, if such actions would have saved Suman's life. Fear of neocolonialism is not a compelling reason to let someone die.

In retrospect, we offer four alternatives that might have saved Suman's life:

- 1 We could have garnered immediate support from the elected village leader to convince the family to hospitalize Suman. However, villagers were aware that Suman would die without medical care, and yet no one, including the leader, intervened. In a region where a girl child is seen as a burden on family's resources, villagers' apathy can be viewed as protecting Suman's poor family from the financial hardships of raising a daughter. Perhaps discrete pressure from local leadership might have supported Suman's mother better in her own desire to save her daughter.
- 2 We could have reported Suman's case in a local newspaper, keeping Suman anonymous but highlighting the dysfunctional CD office, thereby shaming the officer into providing urgent medical attention to Suman. Anonymity would have protected the family and village from the public embarrassment of female infanticide while popularizing community support for Suman's hospitalization and long-term care.
- 3 We could have exploited our stature as US academics to pressure the District Collector into ensuring Suman's survival. The CD officers we contacted were answerable to the District Collector, so he wielded much greater power over them than we did.

- 4 We could have kidnapped the baby and rushed to a nearby hospital, putting aside thoughts about future steps for later, once her health was restored. This act could have meant immediate physical danger from the family and community angered by drastic outsider intervention, imprisonment for kidnapping a minor, and/or negative professional consequences back in the USA.

Research ethics, via courses and the Institutional Review Board process, caution against political situations that might jeopardize the researcher and her institution. We are taught that research ethics entail respect for local culture, suspension of judgment, and non-interfering practices towards informants and their communities. We are trained to come away "clean" from the field, but we are not trained to handle situations that may require radical action based on our politics.

Our training and our politics were not enough to overcome the paradox that faced us. To have behaved ethically, was to have behaved unethically. As feminists, we wanted to respect Suman's mother. As feminists, we wanted a girl child to live. As outsiders, we did not know the social dynamics of the situation. As outsiders, we had the power to do much more than we did. As scholars, we had to behave ethically according to institutional guidelines. As scholars, we wanted to act against injustice.

As radical geographers, our ethical dilemmas were rooted in power and the degree to which we should exert it. Something needed to be done, and we acted, but our reluctance to exert power as US academics led us to favor local advice and pursue the proper channels. As a result, we maintained our ethics as researchers but failed our politics as feminists, scholars, and human beings. We intervened ethically but ineffectively.

Our failed intervention has proven to us that research ethics can be constraining rather than empowering, especially in the practice of politics. The exercise of radical politics is a process saturated with paradoxes, undertaken with uncertainty, and driven by an inner rage. Nothing can prepare us to practice our politics in unexpected situations, but our training as researchers must push us thoughtfully forward into this harrowing process, not hold us back as passive spectators, justifying inaction behind a facade of cultural relativism and power-neutrality.

## Endnote

<sup>1</sup> We are both women holding academic jobs in the USA and having long experience working in poor Indian communities. Richa is an Indian and Kathleen is a white American.