



Methodological Challenges in researching health beliefs and practices of Cancer patients in Assam

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ABSTRACT: Cultural health attributions, beliefs, and perceptions towards health and illness influence cancer patients' health-seeking behaviour and practices. The purpose of this article is to consider the process through which the causal health attributes and the treatment-seeking processes of tobacco-related cancer patients were studied in the Barak Valley region of Assam. Unveiling the methodological issues in conducting the study, this article outlines the dynamics of the hospital as a research setting. The article also discusses the researcher's engagement with the subject and the methods and tools used in the study by unfolding fieldwork processes.

Keywords: methodological issues, research, health beliefs, cancer patients, Assam, India



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Sociology of health and illness is an important domain of inquiry, which examines the interaction between society and the population's health. It attempts to understand how social life and its functioning affect morbidity and mortality, and vice-versa. Diseased people seek medical explanations of their disease and try to understand it within their socio-cultural context (Awasthi & Mishra, 2013; Vaughn, Jacquez, & Baker, 2009).

Cancer, as a fatal disease, has a high level of associated misbeliefs and fear, and the patients have multiple cognitive representations of their illness (Lykins et al., 2008). The representations encompass diverse health or illness beliefs associated with the causality, signs and symptoms, consequences, and treatment of certain diseases (Lykins et al., 2008). The beliefs held by an individual and their family members motivate their health-seeking behaviour and practices. Studies have established a strong association among cultural health attributions, beliefs, and practices (Lykins et al., 2008; Vaughn et al., 2009). Moreover, cultural health beliefs, illness perceptions, practices, and responses directly affect preventive and curative measures (Amzat & Razum, 2014; Stacey & Homans, 1978). Therefore, understanding illness perception and cultural beliefs have been a core focus of health and medical sociology.

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Previous studies on the causality of the diseases have examined causal beliefs regarding non-malignant disease (Lykins et al., 2008). Analysis of some studies (Barbhuiya, 2018; Ten Kroode, Oosterwijk & Steverink, 1989; Timko & Janoff-Bulman, 1985) reveals that very limited research has been done on the ambivalences of cancer patients experience concerning their health beliefs and practices. Further, it is reported that the perceptions surrounding the causality of cancer vary from culture to culture (Peuker, Armiliato, Souza, & Castro, 2016). Besides, there are culturally affiliated risk factors for cancer. For example, in the northeastern region of India, the prevalence of tobacco-related cancers (TRCs) is very high (Sharma et al., 2014). It is associated with the strong cultural affiliation surrounding the consumption of tobacco products. Also, the patients' beliefs, understanding of health, and available treatment facilities regulate their health-seeking behaviour (Awasthi & Mishra, 2013). Thus, the health beliefs and practices complicate, prolong and delay cancer diagnosis and treatment (Barbhuiya, 2018; WHO, 2009 cited in Pati, Hussain, Chauhan, Mallick & Nayak, 2013). All these issues necessitated a comprehensive understanding of the different aspects affecting the health beliefs, practices, and treatment-seeking processes of TRC patients.

The high prevalence of cancers in the northeastern states of Assam, where more than 50% of the cancers are tobacco-related (Sharma et al., 2014), with its unique socio-cultural and treatment-seeking practices surrounding the disease and its different risk factors, make it an interesting subject of exploration in its socio-cultural context. Considering these, the study aimed to seek an understanding of the causal health attributes and the treatment-seeking processes of TRC patients of the state. This article unveils the methodological issues and challenges in conducting the study. It outlines the dynamics of the hospital as a research setting in studying cancer patients. The article also discusses the researcher's engagement with the subject and the methods and tools used in the study by unfolding fieldwork processes.

Researcher's Engagement with the Subject

The thoughts of understanding cancer patient's health beliefs and practices were nurtured when the researcher was working at Silchar Medical College & Hospital, Assam (SMCH) as a Medical Social Worker. At that time, the researcher had worked in an Indian Council of Medical Research (ICMR) granted study on the quality of life and survival pattern analysis of cancer patients in northeast India. As a part of the study, the researcher had interacted with many cancer patients attending the hospital for their treatment. Many of those interactions were done outside hospital premises which gave different sets of understanding about the patient's illness beliefs and

different issues affecting the diagnosis and treatment of cancer. Many of the informal exchanges with the patients informed the researcher about their prolonged treatment trajectory, which was often delayed due to the misinformation and misbeliefs of the patients and their family members. Those factors affected the patient's psychosocial health, which waned even more without adequate psycho-oncological care. Observation of cancer patients' painful journeys and interactions motivated the researcher to understand different matters determining their treatment-seeking practices and subsequent illness-related experiences.

The researcher's previous years of experience working with cancer patients enriched the fieldwork for the study and the researcher's ability to draw insights from the field. Also, the researcher's previous professional contacts facilitated the study in accessing data, support from hospital personnel, and the like. Besides, the researcher's understanding of the local language and issues, as a native of that area, had added productive insights by positively impacting the richness and quality of data. However, the researcher had to remain alert to the possibility of projecting from the previous experiences rather than drawing the data being collected.

Site and Settings of the Research

The study was conducted in the Barak Valley region, located in the southern part of Assam. The Valley consists of three districts (Cachar, Karimganj, and Hailakandi), and it shares borders with three Indian states and an international border with Bangladesh. The Valley is geographically secluded from the rest of the state, and this, along with some other factors, hinders the region's socio-economic growth. Barak Valley is lagging in many fields, including agriculture, industry, infrastructure, communication, and others (Ministry of Panchayati Raj, 2009). The general health status of the region, including the Human Development Index and other mortality indices, was below the state average (Bhattacharjee & Nayak, 2003). Besides, the high prevalence of tobacco consumption (Sharma et al., 2014) and the TRCs in that area (ibid.; PBCR, 2015) and the absence of adequate study on the research concern demanded a thorough inquiry (Barbhuiya, 2018). In addition to these, a strong socio-cultural affiliation and acceptance towards tobacco consumption make it an interesting subject of inquiry in its existing cultural context.

The study participants were drawn from the two main hospitals offering cancer-specific treatments and services in the region, namely, Cachar Cancer Hospital & Research Centre, Silchar (CCHRC) and SMCH. CCHRC is a charitable hospital that provides comprehensive cancer care, and SMCH is the only state-funded referral hospital of Barak Valley providing cancer care. Besides, the Population-based Cancer Registry (PBCR) of Cachar district is located in SMCH, and the PBCR of

Hailakandi & Karimganj district alongside the Hospital-Based Registry is located in CCHRC. Furthermore, the National Cancer Registry Programme establishes collaborating centres for cancer data collection in areas with a high magnitude of cancer. The presence of two PBCRs and an HBCR in Barak Valley signifies the high prevalence of cancer which was also supported by the existing literature.

Methods and Tools of the Study

The high prevalence of TRCs and the unique health beliefs and practices of the study population made it significant to understand the issue's magnitude in a contextual manner. Engaging the dominant approaches of research (qualitative and quantitative) singly wouldn't have helped to have a comprehensive understanding of the extent and nature of the problem and also in understanding the intersectionality of different factors impacting the patients' health beliefs and the treatment-seeking practices. Keeping these in mind, the study was conducted in two phases using a combination of quantitative and qualitative methods. Explanatory Sequential Mixed design was adopted, considering its usefulness in explaining and interpreting cancer patients' unique health beliefs and practices contextually by supporting the quantitative results with the patients' narratives. Also, the pragmatic worldview of the mixed method allowed the researcher to use multiple methods, different assumptions, different forms of data collection and analysis. The study began with the broad quantitative phase for generalizing the findings to the population of the study and then studied the startling results of the initial quantitative data in detail with the help of the qualitative approach in the latter phase. Thus, a comprehensive understanding of the research concern was possible with this philosophical worldview.

The primary data source for the study was TRC patients of Barak Valley attending either CCHRC or SMCH for their treatment. The dataset included socio-cultural, economic background, health beliefs, attributions, health-seeking practices, and the resulting experiences. The data collection comprised of two phases. In the first phase, quantitative data was collected and analyzed, followed by collecting and analyzing qualitative data in the latter phase. Thus, 100 TRC patients were interviewed from both hospitals as a part of quantitative data. Based on the analysis of those quantitative data, the second phase of the study was designed where the patients having diverse treatment-seeking experiences along with different health beliefs and practices were incorporated as a part of the sample. Thus, 11 patients were included in the qualitative phase.

For drawing quantitative data, the researcher used standardized interviews. Standardized interviews were helpful to maintain the same context of questioning for all the 100 patients. Thus,

attempts were made to provide the same or similar interview stimulus for all the patients significantly. The goal of that interviewing method was to ensure the aggregation of the interviewee's responses reliably, as explained by Bryman (2012). The standardized interviews were administered using an interview schedule. Considering the participants' awareness, literacy level, and the study's context, the interview schedule was found to be appropriate for data collection. Also, the Self-Reporting Questionnaire-20 (SRQ-20) of the World Health Organisation (WHO) was incorporated in the interview schedule as a screening instrument to study the psychiatric morbidity of the patient. SRQ-20 is used to screen for psychiatric disturbances in primary health care settings, especially in developing countries (Harding et al., 1980 c.f. Ali & Jaswal, 2000) for the underserved populations. Looking into the socio-demographic and geographic vulnerability of the participants, this instrument was considered suitable for the study.

To collect qualitative data in the second phase of the study, an interview guide was used to conduct in-depth interviews. The use of in-depth interviews provided detailed and comprehensive information about the participant's illness-related experiences. Silverman (2006) described that in-depth interviews procreate emotionalist and constructivist knowledge by addressing the research concerns. Thus, that method helped the researcher to understand how the participants constructed their social world, attributed meanings, and interpreted several aspects related to cancer, its diagnosis, and treatment alternatives. Besides, both the tools were validated by a pilot study before initiating the data collection. Thus, the researcher made necessary modifications before dwelling in the field. Further, the data gathered through the interviews covered areas related to socio-demographic factors, illness, history, health beliefs and attributes, health-seeking behaviour and practices, and the patient's psychosocial health status.

Unfolding the Fieldwork Process

Fieldwork with cancer patients in hospital settings was one of the fascinating periods of the study. It provided new insights about the subject of enquiry, the field, and the study participants. The researcher's prior work experience in SMCH helped develop a roadmap for getting data relating to the illness-related experiences of cancer patients of Barak Valley. The researcher applied to the Principal-cum-Chief Superintendent of SMCH for permission to collect data, which was given after around three months, following many visits to the hospital to meet senior officials and the approval from the ethics committee. The SMCH officials also asked the researcher to get an order from the Director of Medical Education (DME), Assam. Following that, the researcher met the DME after making several attempts to discuss the study, its opportunities, limitations, and the

needed support for undertaking the study. Thus, after spending around a month, the researcher got the permission letter from the DME addressing SMCH for their support in conducting the study.

While approaching the Director of CCHRC, their recommendation was to make a research proposal presentation before the ethics committee and get their approval to start the data collection. Accordingly, the researcher presented the proposal to the ethics committee, where there was much discussion around the contents of information sought for the study and its impact on the patients' psychophysical health. At that time, the researcher had some dissents and discussions with the oncologists and a few medical professionals on looking at the general health of cancer patients, who looked at the subject through the biomedical lens. Even in the era of the bio-psychosocial model, which recognizes the interaction of psychological and social factors with biological factors in causing illness (George & Engel, 1980), the physician's viewpoint was largely biomedical. They considered the disease to be mainly caused by a biological factor, where the patient's understanding (subjective) of the illness, their experiences, and the resulted distress are overlooked. Besides, they were critical when the researcher proposed to seek information to understand the medical authority and social power of oncologists/ doctors in influencing cancer patients' treatment decisions and illness trajectory. Based on the suggestions of the ethics committee members, some changes were made to the data collection tools.

After fulfilling the requirements as mentioned earlier, permission was granted to initiate the data collection process. Then, the researcher began the pilot study with 8 TRC patients to evaluate the tool's validity. Based on the pilot study findings, a final round of modification was done in the interview schedule. Thus, after spending four months, the researcher went on to start the actual data collection. While completing the requisite procedures, the researcher also spent some time interacting with a few oncologists, medical social workers, and staff nurses to overview cancer care, services, and different challenges in Barak Valley. Those interactions enriched the researchers' understanding of cancer patient's difficulties and locating their issues within the broader discourse of health and illness.

On understanding the broader picture, the researcher initiated the first phase of data collection (quantitative) in the hospital premises. As proposed, randomly, 35 samples were drawn from the list of the patients availing treatment from the Dept. of Radiotherapy, SMCH. The researcher's relationship with the radiotherapist of SMCH helped access the list of cancer patients availing treatment, which was used as a sampling frame for simple random sampling. For CCHRC, the ethics committee did not permit to use simple random sampling technique to draw samples

considering the floating nature of the patients attending the hospital for treatment. They also opined that the particular sampling technique might affect the treatment flow of the patient in the hospital. Following their suggestions, the researcher adopted a purposive random sampling technique in drawing 65 samples from CCHRC, based on some inclusion criteria, including age at diagnosis, site of cancer, kind of treatment accessed, and experiences with the medical treatment. Besides, the participants attending CCHRC for cancer treatment were around double than those attending SMCH. So, for maintaining the equal proportion and population representation, 65 samples were taken from CCHRC and 35 from SMCH. Thus, 100 samples were drawn from both hospitals with the help of a mixed sampling method.

The first phase of data collection was both interesting and tedious also. The researcher had to start the data collection process early in the morning at around 8:30 AM, and most of the time, the process continued till late evening until 7:30-8:00 PM. It was a real challenge to commute at night when proper transport facilities were unavailable in a small town. Besides, there were times when the researcher had to wait for the whole day to interview a single TRC patient, and sometimes the researcher had to come back with an empty hand after spending 11-12 hours in the hospital. On the contrary, there were days when the researcher was overburdened with an ample number of cases. Thus, the researcher completed the quantitative phase of data collection with mixed experiences and enormous learnings.

The collection and basic analysis of quantitative data were followed by collecting qualitative data in the latter phase. With the analysis of quantitative data at hand, attempts were made to identify outliers for further in-depth exploration who behaved differently from others and had diverse illness-related experiences concerning the causality of cancer and the treatment-seeking processes. Also, the researcher considered other criteria for the inclusion of samples such as age at diagnosis, site of cancer, nature of the treatment, treatment status, experiences with the treatment and physician, availability, and kinds of social support and network. Based on these criteria, 13 participants were identified for in-depth interviews using the purposive sampling technique. Of those, two participants died before their inclusion in the study. So, finally, 11 participants (five from SMCH and six from CCHRC) were incorporated in the qualitative phase. In-depth interviewing was in tandem with observational strategies of the researcher to understand the participants' pattern of response. Thus, observing the participants' reactions when asking some specific questions had helped the researcher better understand the nuances of the participant's illness-related experiences. Interviews averaged 65-70 minutes in duration. Besides, seven in-

depth interviews were conducted in the hospital premises, and the rest four were undertaken at the participant's residence.

The research setting, particularly where interviews are undertaken, influences the study participants' responses and behaviour. Doing in-depth interviews with cancer patients was fraught with methodological and ethical challenges. The idea of using qualitative in-depth interviews in hospital settings can be questioned. Schlosser (2008) admits the limitations of using ethnography or participant observation, or in-depth interviews in institutional settings. The author also pointed out that the data emerging from a brief encounter in such settings through the medium of narrative can be as rich as what can be obtained from any other method. The interactions done in the hospital setting were relatively more formal than those held at the participant's residence. Even if the participants had unpleasant experiences concerning the hospital or doctors or some sort of medical advice from the doctor, they did not prefer to open up. In those cases, interviews in places other than the hospital settings were found to be a better platform for more in-depth and critical information.

Moreover, while interviewing in the hospital premises, the researcher attempted more informal conversations to extract more relevant in-depth information. For a few participants, especially women, it was found to be a successful strategy. The researcher also actively observed the participants, their body language, the pattern of response to the questions posed, patient-physician communication, and the like. Thus, attempts were made to understand the participant's unexpressed words and experiences by capturing non-verbal communications and other interactions. Besides, there were hurdles in interacting with those participants whose health condition was very critical and who had difficulties having a conversation. In such cases, the researcher had to spend more time conducting interviews with the caregiver's assistance (s). That's how the researcher had to make some changes in the fieldwork strategy considering the practical issues affecting the participant's health and healthcare and thus impacting the overall data collection processes.

The Dynamics of Hospital as a Research Setting

Researching in different settings has its unique pros and cons. Collecting data in an institutional setting is more structured and formalized against the community setting, which is more flexible. Again, the functioning and flow of information in an institutional setting are more systematic and consistent. However, the hospital as a research setting, mostly dominated by doctors and clinicians with a biomedical worldview, is unique. Getting the initial permission for

conducting a social science study and considering the study to be a significant one is not an easy task in a setting where biomedical worldview plays a dominant role. The same happened with the researcher while convincing the doctors attending the ethics committee meeting at SMCH and CCHRC about the study's implication on cancer patients. Again, some of them were skeptical about the psychophysical impact of the study on the patients' overall health and their flow of treatment in the hospital. The researcher had to convince them following lots of discussions around the subject of enquiry and the subject of the study. Thus, getting official permission for data collection in a hospital setting (particularly in an oncology ward) was an uphill task that consumed around four months.

Entering a hospital with official permission and getting introduced to the research participants through medical professionals have advantages and disadvantages. While access to the participants and the required information becomes easier, it could be detrimental to the study, as the participants tend to view the researcher as an outsider with power, and that perception may colour their decision to be interviewed. Raghavan (2017) also highlighted similar kinds of challenges in studying the underworld. While studying prisoners, Schlosser (2008) also pointed out similar encounters. In that context, it is important to explain to the participants that the researcher has no connection with the power structure or data collection organization. Considering the significance, at the beginning of each interview, the researcher properly introduced himself, the study and its' purposes, and related matters to the participants and their family members or caregivers, when required.

Participant information sheets and written consent were the two important instruments that the researcher used carefully before starting the interviews. With due importance, the researcher filled the written consent form for all the interviewees, except those critically diseased with difficulty paraph or put thumb impression. For them, oral consent was taken, and the other necessary aspects were accomplished with the help of the caregiver(s) accompanying them. The emphasis on written consent was because of the recommendation of the hospital's ethics committee and the prevailing of such practices in health research. But, the practice of written consent, including the use of thumbprints for illiterate participants, has certain disadvantages against verbal consent. Some studies have reported that the participants might think that the process might have legal implications or be deceived, which may, in turn, develop mistrust about the study (Marshall, 2007 as cited in Regmi et al., 2017). Therefore, the researcher explained in length the study's ethical considerations, including the participants' rights to withdraw from the

study at any point in time. Also, whenever the researcher approached the patients for their interview, at no point in time, even during their rush hours, they disagreed with the same. That might be because of the hidden social power of the researcher, which was perceived by the patient when the health professionals introduced the researcher. Another important factor behind that perception could be the interview being conducted on the hospital premises. Some of the patients might feel that their treatment-seeking processes would be affected if they did not give an affirmative response for the interview. Thus, the hospital as a research setting was putting some amount of compulsion on the participants, deflection of which was not possible for the researcher after detailing and clarifying every nicety about the study.

Building relationship with the participants in the hospital setting has its limitations. Developing rapport with cancer patients in the hospital setting was difficult due to the floating nature of the population and the fact that they were in a stressful situation. Tracing new entrants attending the outpatient department (OPD) of the hospital was difficult. Besides, there were days when the researcher had to delay the interview process considering the rush in the OPD, and the researcher had to wait for hours to interact with the participants. Also, there were some times when the hospital staff interjected in-between the interview sessions, affecting the interview flow. Although there were some unique limitations of conducting a study in a hospital setting, there were many advantages concerning the logistics related to the study participants' access, the space of interview, and others. In both the hospitals, the researcher got a specific space for conducting the interview sessions, which helped maintain privacy, confidentiality and safeguarding the participants' interests.

Interacting with cancer patients in hospital settings for the study's data collection brought a unique set of experiences. The participants' physical and mental health condition, experiences with their treatment-seeking processes, interaction with the health professionals and health system, articulation abilities, and the place of the interview had a crucial bearing on the length of the interviews. Some were very articulate and had a lot to share that prolonged their interviews, while others were cryptic. Besides, some participants shared their experiences in detail, and they did not want the researcher to record that information. That could be because they perceived that if the information was documented and further shared with the hospital authority, it could affect their smooth treatment-seeking processes in the hospital. Understanding those concerns, the researcher ensured those participants again about the research ethics, including the anonymity and the confidentiality that would be maintained. That's how, with some pros and cons associated

with the subject and settings of the research, the researcher completed both phases of data collection.

Challenges and Limitations of the Study

This study, like other studies, suffers from some methodological, field, and fieldwork-related issues. Getting necessary permission from the respective hospital authorities and DME were arduous tasks that took around four months, resulting in delays in data collection. Further, the fieldwork and in-depth exploration of data required developing rapport with the participants, which was difficult given the floating nature of the population in the hospital. It was because the participants under treatment are mostly under a stressful situation and were unable to fully open up with the researcher. Hospital as a research setting, where most of the interviews were undertaken, has also added a lead to the fact. Besides, the OPD patients were difficult to trace after accomplishing their hospital visits for a second setting, if required, especially in the absence of full address and contact details. Further, the timings of fieldwork or interaction with the participants concerning their treatment/ illness trajectory had lots of things to do with the nature of the data. For example, the psychiatric morbidity and the illness-related experiences that were sought in the study varied for a patient from time to time, concerning the participant's phase and kind of treatment, positive or negative impacts of that treatment, physical condition at the time of the interview, participant's prior interaction with the health personnel or the medical system.

The lack of grounded research and literature about the study phenomenon in the Indian context was another limitation. Most of the studies and theories reviewed for this research have been conducted in the western context. To overcome those limitations, the researcher attempted to contextualize the understanding of cancer patient's health beliefs and practices through an in-depth exploration of those participants who had diverse health-seeking experiences and then using those data to support the positivistic dataset. Another limitation included in the study is the TRC patients of Barak Valley who attended the two main hospitals for their cancer treatment. In this case, the findings were restricted to the specific cancer sites and establishments of accessing cancer treatment. Another barrier was that this study focused only the cancer patients. The involvement of other stakeholders engaged in cancer care and services, such as oncologists, psychologists, nurses, medical social workers, and the patient's caregivers in the study could have provided a comprehensive understanding of the research problem. In addition to that, the information from cancer survivors and those with a family history of cancer were grouped regardless of cancer type, stage, or duration of treatment. These factors might bring changes in

the patient's representation of illness.

Furthermore, this study did not examine other factors influencing patients' health attributions, like cultural affiliation of risk factors or the social construction of cancer. Limitations of this study also include not cross-checking a couple of common-sensual responses like God's will, destiny, or bad luck. Finally, the settings where interviews were conducted had lots of effects on the kind of responses gathered. The researcher didn't consider these factors in the analysis of data.

Conclusion

Conducting a study with people diagnosed with cancer was an interesting and challenging journey. Spending long hours daily in the hospital setting, interacting with them, and witnessing their critical psycho-somatic difficulties was a breakthrough in learning sensitive and serious matters associated with health sociology. The outstretched fieldwork processes for the study, including meetings with the hospital authorities, DME, presenting the research proposal in the ethics committee of the hospitals, dissenting and discussing with medical professionals on the biomedical model of health, had enriched the researcher's learning.

The use of mixed methods in studying the research concern opened up the gateway for applying multiple methods, tools, and techniques to collect and analyze data, resulting in a comprehensive understanding of the TRC patient's health beliefs and practices by exploring the extent and nature of the phenomenon. The use of Kleinman's explanatory model, as one of the study's theoretical approaches, helped understand the patient's perspective of health and illness and how that perception led to the choice of a particular form of treatment. Also, the Andersen Model of Total Delay was referred to understand the delays at the patients' level in seeking treatment throughout the different phases of treatment and medical decision-making. Thus, different assumptions and methods of quantitative and qualitative approaches were brought together to understand the participant's health attributions, beliefs and practices.

Given the lack of studies on the sociology of health and illness in the field of oncology in the Indian context in general and north-east in specific having its unique beliefs and practices surrounding cancer and its risk factors, this study has attempted to make some useful contributions in the theoretical and methodological dimension of the research concern. The study has deepened the understanding of cancer patients' causal health attributes, beliefs and practices, and their effects on their psychosocial health. It also has broadened the horizons of fieldwork with cancer patients in hospital settings. Thus, in addition to deepening the researcher's understanding

of the prospects of the phenomenon under study, it has broadened the horizons of the field of health sociology. The study may develop interest among researchers for further exploration into the subject considering the findings and limitations of the study and help in theorizing around the subject.

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