

Ethical Considerations in Social Sciences: The Dilemmas of Informed Consent

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Abstract

Informed consent is an integral component of research ethics in Social Sciences. It has been observed that in Pakistan, most of the research ethics have been borrowed from the Western context. Therefore, it is vital to see how research ethics are being construed and practiced in Pakistan having different socio-cultural values and norms. In the case of informed consent, the bigger question is 'how informed the informed consent is?' Thus, in this paper, through a qualitative exploratory approach, we have explored how active Social Science researchers in our universities, see the notion of informed consent. We interviewed eighteen university teachers for the study. Transcribed the interviews verbatim and analyzed those using robust qualitative approaches. Findings show that 'informed consent' becomes a dilemma for the researchers given the variations in the socio-cultural and linguistic contexts of the settings. Findings have pertinent implications for policymakers, university management, and researchers in the context of Social Sciences.

Keywords: Research Ethics, Informed Consent, Ethical Considerations, Social Science Research, Qualitative Studies

Background

Social Science research mostly deals with human beings. Humans are conscious beings and have multiple identities in their families, in institutions, in society, and the world over (Cole & Knowles, 2001). It is therefore imperative to consider the research ethics very seriously and carefully. In the context of research ethics, Social Science researchers generally look into several aspects of the research studies. Those aspects include the worthiness of the research project; boundaries of competence; informed consent; benefits and reciprocity; harms and risks; honesty and trust; confidentiality, privacy, anonymity; integrity, quality; data ownership; and uses and misuses of results (Miles & Huberman, 1994).

Literature has identified that the onus of carrying out ethical research lies with the researchers who conduct the studies (Merriam, 1998); therefore, in Social Science researches, the role of researchers becomes crucial. A researcher needs to be vigilant from the planning phase to the end. The following questions highlighted by Khan (2009) can help to ensure some basic elements of ethics in a Social Science research study:

- Is the research project worthwhile?
- Has the researcher clearly understood the research process and can carry it out successfully?
- Does the researcher have the relevant knowledge and appropriate expertise to carry out the study?
- How should the researcher negotiate consent for the study?
- How can the researcher complete the research process without harming the research participants?
- What cultural aspects does the researcher need to consider during the study?
- How will the researcher ensure the confidentiality and anonymity of the data and the informants?

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- How should the researcher disseminate the findings without harming the research participants?

Hence, the researchers must be well aware of the research ethics in their respective fields and have designed the studies carefully considering the core values of research ethics and moral obligations (Gilligan, 1983). Ironically, most of the research ethics have been developed in the West and there has been a scarcity of studies on social science research ethics from an Eastern perspective. As a result, there is a sole dependency on the West in connection with the research ethics in Social Sciences. As the cultural norms and values are different, societal aspects are different, and the social behavior of people in the eastern Muslim societies vary from those of the West, therefore, there is a need to develop Social Science research ethics considering the norms and values in the Eastern Muslim societies.

In the case of informed consent, the issue becomes further complex. This paper; therefore, has put forth some key findings from a study in making sense of ‘informed consent in the Social Science research ethics. The study was carried out in Pakistan through in-depth interviews with eighteen university teachers from the Social Science faculties in universities.

Literature Review

With the historic development of Social Sciences in the West, concerns regarding individual liberty and neutrality emerged in the social institutions (Root, 1993). Today, research ethics have become a key component of the review process of any Social Science research work. Research ethics are generally nested in contexts of the respective disciplines. Therefore, Social Science research ethics are nested in the context of Social Science where liberty, equality, and justice are the key elements (Jane et al, 2013).

It is a common belief that research ethics are important for the promotion of the aims of research in society for the development of knowledge, ensuring trustworthiness, and avoiding possible errors. Ethics also guides the promotion of values for collaborative work including trust, accountability, mutual respect, and fairness (Christians, 2002). Likewise, research ethics also make the researchers morally accountable to the public for the quality and integrity of the academic work (Habermas, 1990). Ethics also becomes instrumental to the establishment of public support for research and the promotion of important moral and social values.

With the emergence of ethics in Social Sciences, various guidelines and directives surfaced. Those guidelines include informed consent, deception or misrepresentation, privacy and confidentiality, and accuracy (Darlington & Scott 2002; Denzin, 1989; Rossman & Rallis, 1998).

Informed consent is a key element in research ethics. However, a general question is, how informed is informed consent? Or how much to inform and how to inform? Researchers share with the research participants an information sheet about their studies highlighting possible harms and issues and benefits owing to participation in the studies (Darlington & Scott 2002; Rossman & Rallis 1998). Based on the information shared with the participants, consent for participation in the study is sought from them. It is imperative to negotiate various aspects of the studies with the research participants and allow them to participate in their will.

Deception or misrepresentation of data and findings have no room in Social Science research. Deception is against the social, and moral, and academic values and obligations (Heller, 1990). Misrepresentation or misinterpretation of data leads to deception. Flaws in research tools, data collection approaches, and carelessness during analysis also result in deception in studies. Deception can occur through conscious and unconscious attempts, thus misleading the findings of the studies. It is the moral responsibility (Root, 1993) of a researcher to be aware of the deceptive elements in the study and to address them carefully.

Ensuring privacy and confidentiality is also an important aspect of Social Science Research (Darlington & Scott, 2002; Merriam, 1998; Rossman & Rallis, 1998). Denzin (1989) highlights, “we must remember that our primary obligation is always to the people we study, not to our project or a larger discipline” (p. 83). Likewise, ensuring data accuracy is vital too. Accurate data would yield accurate and authentic findings. Thus, it is important to collect error-free data.

All the research ethics were initially developed in the West based on the moral obligations and concerns of the academic work (Bok, 1995). With time, Institutional Review Boards (IRBs) (Vanderpool, 1996; Cleaton-Jones, 2019) were introduced to monitor and oversee the ethical considerations of research conducted by the respective institutions. Protecting the institutions, as well

as the research subjects or participants, is seen as the core purpose of the IRBs. However, there is a need to explore to what extent the IRBs perform their due roles (Grady, 2019). Likewise, the establishment of the Research Ethics Committee (REC) is also common in universities to regulate, monitor, and oversee research ethics (Davies, 2020). Likewise, in Pakistan, universities have committees or boards for ethical review with various names and compositions. The task of such committees or boards is to develop policies for research ethics, implement them, and check on the ethical concerns in the research studies that involve human subjects. However, there is a dire need to develop ethical policies, procedures, and guidelines for the research work, in general, and for Social Science Research, in particular at the national level.

Research ethics becomes crucial and vital when employing narrative studies and biographies (Cole & Knowles, 2001; Goodson & Sikes, 2001; Khan, 2009) as such studies involve participants' personal and professional life experiences. It is likely that the opposite gender of a researcher and a research participant may impact the authenticity of data generation, particularly when conducting narratives biographic studies (Cole & Knowles, 2001; Goodson, 1992a; Halai, 2002).

Likewise, involving children and young people in social science research also has huge ethical implications. Children's voices should be heard, and they should have the right to participate in research studies based on prescribed research ethics (Alderson, 2000; Alderson, & Morrow, 2011). Since, children under the age of 18 need their parents' consent or *in loco parentis* (Freedman, Fuks, & Weijer, 1993) in decision-making for the participation in research studies; therefore, there is a need to devise a comprehensive mechanism of research ethics in this regard.

Methodological decisions

We employed an interview approach of the interpretive paradigm (Denzin, 1989) to conduct the study. Being conducted in the natural setting, researcher(s) being the key source of the data generation, and in-depth nature of the interpretive paradigm (Merriam, 1998; Rossman & Rallis, 1998), the qualitative approach enabled us to get a deeper sense of the phenomenon that is, making sense of the research ethics in the Eastern Muslim context. Eighteen university teachers, ranging from lecturers to full professors from the faculties of Social Science and Humanities, participated in the study. All the research participants were active researchers who had published their works in various national and international journals.

We generated data through interview protocols having semi-structured interview questions. We conducted 26 interviews in total (including initial and follow-up interviews) with the twenty-two research participants. The eight follow-up interviews were conducted to get the required clarifications. The duration of the interviews ranged from 45 minutes to 60 minutes each. We also probed for further clarifications wherever needed during the interviews and asked the research participants to give examples from their relevant experiences. We audio-recorded the interviews using a device and transferred the audios to a computer. We then transcribed the audio records verbatim and used them for the analysis. We also shared the transcriptions with the research participants for validation purposes.

Analysis of the data involved a staggered plan beginning with the preparation of the transcripts, reading through them several times, developing marginal notes and codes, and developing research memos. The various research memos were then turned into themes and sub-themes. Since the bilingual approach (Urdu and English) were used for the interviews and all the interviews were transcribed in the corresponding languages. All the Urdu extracts from the interviews, used in this paper, were translated into English for dissemination purposes. In this case, both the original extracts and their corresponding translations were given to experts to assess the quality of the translation. The experts were at home in both languages. Upon their feedbacks, the extracts were then used in the paper. We had made a conscious attempt to translate the extracts without changing the gist.

Research ethics were thoroughly taken care of during the study. We took consent based on sharing of information (both oral and written) with the participants, used pseudonyms, protected their identities kept the data anonymous. We stored the data in lockers and did not share them (audio records and transcripts) with anyone else.

Findings

Based on the rigorous analysis of the data, findings have been presented under various sections below.

The tradition of a verbal consent

It surfaced from the interviews that generally people resist signing the consent form; they rather prefer verbal consent. Thus researchers face challenges in studies where written consent is mandatory. The following are key extracts from the interviews.

- “We traditionally live in a trust-based society. Two third of our population live in a rural setting where signing a written document is seen as a sign of mistrust and a violation of trust and confidence.”
- “I conducted my Ph.D. fieldwork in a remote village. Getting a signed consent was mandatory as per my university policies, yet the villagers were afraid of signing the consent. They were ready to participate, yet reluctant to sign the document. This initial entry into the field was a huge challenge for me.”
- “A researcher faces dilemmas in signing the consent during the fieldwork. It is also true for urban society too. For instance, one of my study fieldworks was based in Karachi, a big city, where I also faced challenges in getting the consent signed.”
- “Signing the consent form becomes a huge challenge in an ethnographic study. Knowing about the signing of the consent, the people feel hesitation and the natural setting gets disturbed.”

Thus, it came up from the above extracts that getting a consent paper signed by the research participants becomes critical in a traditional culture of trust where conventional approaches of verbal agreements are in practice, and where the signing of documents implicitly denote an element of mistrust. Hence, researchers tend to face dilemmas in pursuit of written consent. It surfaced that in the rural areas people take it negatively and see it as a sign of mistrust when a researcher asks for a written consent as a requirement of the IRB process. This has raised implications for the IRB process and requirements.

Consent from the family

Almost all the research participants highlighted that women research participants generally tend to resist giving consent on their own; rather, they consult their family elders such as father, elder brother, or husband before deciding to participate in research studies. The following extracts from the interviews further highlight the concerns.

- “I have noticed during fieldwork that women generally become hesitant to give consent to participate in a study without the permission from the elderly male member in her family. Unless they get permission from the family, they cannot give their consent for the participation.”
- “In a study, both men and women teachers were my research participants. I observed that most of the women teachers did not participate in the study without the permission from their families.”
- “Women participants generally resist giving consent to audio or video recording of their interviews. And in case of asking for written consent, it becomes more challenging.”
- “In case of research participants being below the age of eighteen, it is important to get the consent from their parents or guardians. I have noticed that teachers also resist giving an in-loco-parentis consent for their students.”
- “Educated women are more conscious about giving consent to participate in a study. It could be because of more awareness about the misuse of the data. However, when they know the importance of the study, they willingly give consent.”
- “In a study, women research participants took the Urdu translation of the information sheets about the study to their families and shared them with the family heads. Upon the directives of the family heads, some of them participated in the study and others refused.”

The consent of women being dependent on the permission of family members, particularly the male members of the family, is deeply rooted in the traditional cultural norms and values. Given an unseen fear of *izzat* (honor) women in the traditional culture resist giving written consent to participate in various research studies. In the case of male researchers, the issue becomes further challenging. As a result, either they resist their participation or take permission from the family elders before taking their decisions to participate in research studies.

Language of the consent

Two types of dilemmas, faced by the researchers, emerged from the analysis of the data: a) technical language and b) spoken language. Technical language refers to the language of research only known to the researchers; whereas, common people are not familiar with it. Thus, explaining the pros and cons of the research during the entry negotiation becomes a real question. The second type of challenge was related to the language differences of the researchers and the research participants. The following are the key extracts from the interviews:

- “Explaining various research terms to the non-research fraternity is a real challenge to get the consent.”
- “Language is an important tool of communication. The language of research is different from the common language. Thus, explaining the pros-and-cons of the research to the participants for their consent is a real challenge.”
- “During fieldwork in a particular province, it was a huge challenge for me to speak the language of the local people. I translated the consent form and information sheet in the local language, yet I was not sure about the accuracy of the translation.”
- “The information we share with the research participants for informed consent is likely to mislead if it is not carefully handled. It is more critical in case the researcher and research participants speak a different language and if they communicate through a translator.”
- “The role of a translator is also questionable. If the researcher and research participants communicate with each other through a translator, it is very challenging to know whether or not the translator communicates the message without changing its essence.”

Numerous languages are being spoken in the country. It becomes a challenge for researchers to make sense of the languages of the participants and to explain things to them in their languages. This raises questions related to informed consent. Similarly, the issue of the translation of the consent form and the information sheet was highlighted by the researchers. The findings have raised questions about the effectiveness of the translations and the role of translators. For instance, how effective a translation can be in terms of its accuracy and appropriateness and how much to rely on a translator.

Cultural and gender concerns

The role of cultural norms and values also emerged as key dilemmas in the ways of getting informed consent in Social Science researches. The norms and values become considerably more overarching in the case of getting consent from women participants. The following are the most commonly emerging extracts from the interviews.

- “Research is an alien thing for the common people in our context. Mostly, people get scared when you request them to participate in a research study. For informed consent, it is important to share details of the research with the participants. This sharing of details sometimes makes people scared and they resist participation.”
- “As per the research policies and rules, it is mandatory to avoid conducting interviews publicly. Thus, interviewing the opposite gender in a private space creates a cultural challenge.”
- “Gender of a researcher is critical in ethnographic studies and biographic genre. Thus, in such studies, getting consent and carrying out fieldwork as per the research rules, are challenging due to cultural restrictions. People in the villages get hesitant to interact with a person of the opposite gender.”
- “Our people are most familiar with survey researches and qualitative studies are rare in the context. Thus, when you request people to participate in long interviews or longitudinal qualitative studies, they get reluctant to participate.”

Thus, a patriarchal society seems to impact heavily on the decisions of participating in various research studies. As a result, women participants consult their elders in the families before making their decisions to participate. In addition, research culture, particularly the qualitative research culture, has not yet had its roots fully in society. People hardly have some information about survey research studies, therefore, when they are requested to participate in longitudinal qualitative research studies, they resist their participation. It is partly because of fear of sharing their personal views, perceptions, or beliefs with anyone else or because of time constraints.

Discussion

Findings showed that social science researchers were vigilant, careful, and cautious about the informed consent for the participation of people in the research studies. They faced the dilemmas nested in the socio-cultural norms and values (Khan, 2009). The researchers thus seemed to be skeptical about the very notion of informed consent. The common question that surfaced was ‘how informed is the informed consent?’ Conventional or traditional norms and values of culture, the patriarchal norms of the society, and multilingual society seem to make the consent more complex and questionable. Such factors have huge implications for social science research studies. Researchers need to take careful steps in terms of providing detailed information about the study, building mutual trust, spending more time in the field, and establishing a professional relationship with the research participants (Miles & Huberman, 1994).

It was found that understanding of language and the research context play an important role in negotiating entry and getting consent for participation in the studies. Such findings reinforce the dilemmas and concerns commonly faced by qualitative researchers in the interpretive paradigm (Cole & Knowles, 2001; Denzin, 1989). Building professional rapport and a trustworthy relationship with the research participants become more critical when the researchers are not aware of the languages spoken by the research participants. In such cases, researchers employ the services of a translator. This raises the question of accuracy in the communication because communication through a mediator/translator may not be as accurate as first-hand communication. Thus, the question is, how the researcher knows whether or not the message has been communicated and received with the essence of the original discourses.

Norms and values of the larger social culture seem to influence the entry negotiations and getting informed consent from the participants. For instance, research participants of the opposite gender tend to resist their participation. In such cases, they need permission from the elders of their family. Rural context, multilingual society, limited literacy rate, and absence of the familiarity with research work by the common people, perceptions of people about the research seem to influence the informed consent. However, this could not be the issue in the Western context.

Given the deep-rooted norms, values, customs, and belief systems in the context, the notion of ‘informed consent’ becomes questionable. Researchers need to be aware of global research ethics, human rights concerns, human dignity, and freedom as well as the contextual realities where the studies are being carried out (Jane et al, 2013). Research ethics should be key elements of courses on research methods in the universities and degree awarding institutions. The role of IRBs should not only be the monitoring and certifying bodies; rather, they should engage with the researchers to educate them about the research ethics to enable them to become conscious, knowledgeable, well-aware, careful, and skillful researchers.

Findings have implications and recommendations for the research communities in Social Science. It is vital to devise research ethics considering the contextual realities and norms at the national and institutional level. Such ethics should be based on the bedrock of global ethics, on the foundations of basic human rights, and freedom. Universities can play a lead role to develop policies and procedures on research ethics in social sciences, disseminate them widely for critiques and feedback. Such efforts will become instrumental to the development of unified and contextually relevant policies and procedures.

Conclusion

This small-scale qualitative study has explored the notion of research ethics in general and that of informed consent, in particular, in a patriarchal Eastern society. Findings have showcased the contextual realities that the Social Science researchers face in pursuit of getting informed consent. Cultural norms and values, multilingual society, researchers’ gender identity, and technicality of the research language, and lack of awareness and information about qualitative research studies in the society, seem to be the causes of dilemmas faced by the researchers in the Social Sciences. Findings have pertinent implications for the Institutional Review Boards (IRBs) in the universities and all other research-oriented organizations. Findings have put forth recommendations to develop research ethics at the national level through the involvement of universities in the process. In doing so, it is vital to consider the larger socio-cultural context of the country.

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