BIOETHICAL ISSUES IN THE WAKE-UP TO COVID 19: A DEONTOLOGICAL VERSUS TELEOLOGICAL TUSSLE IN NEPAL; A METAETHICAL PERSPECTIVES.

(PRESENTED AT 17TH WORLD CONGRESS OF BIOETHICS IN DOHA, QATAR)

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Introduction

- Ethics is a conceptual domain which talks about morality, values and principles to govern the professional work.
- Medical ethics are those moral principles that govern the practice of medicine and followed to treat the patients.
- Similarly, bioethics is a concept which followed the principles while conducting biological research for medical purpose.
- Metaethics is the branch of analytical philosophy that explores status, foundation and scope of moral values, properties and words.

Conceptual Framework

• The word: 'deontological' comes from the Greek word deon, which means 'duty'. Hence it is also called: 'duty-based ethics' (Saadhan-Saadhya).

In contrast, teleology is the study of teleos (ends) or purposes, which is also known as consequentialist ethics (Saadhya).

Conceptual Framework

- Bentar (2003), "Ethics is about a relationship and as relationships involve considerations of power, there is an intimate link between ethics and power.
- Power is generally conceived of as influence over others....the nature of power in healthcare is of additional particular concern because it relates to having access to intimate knowledge about people that can be used to expose and exploit the vulnerability.
- All of us are vulnerable and can be hurt by others. When information about our bodies or our bodies or our mind is made public we are particularly vulnerable. Hence, the importance of confidentiality and trust in the encounter with professionals".

The Context - Problematization

- The oropharyngeal swab of the first COVID infected case returned from Wuhan, China has been sent to the WHO reference laboratory in Hongkong for PCR test.
- In this case, the RT PCR result came positive for that particular individual. However, after a month, the result of gene sequencing has been published in the microbiology resources announcement, an online journal published by the American Society of Microbiology on March 12, 2020.
- After the journals have been published, the concerned authorities of the Nepal health research council (NHRC) have noticed that this particular gene sequencing process has been done without any ethical approval.

Methodological Framework

- Critical discourse analysis focuses on the investigation of the ways in which social-power, dominance and inequality are practiced, reproduced, and sometimes resisted through the inspection of several forms of communication in relation to social and political contexts (van Dijk, 2015).
- Critical discourse analysis integrates studies from different perspectives and methods in discourse studies, including conversation analysis, argumentation analysis, discourse pragmatics, multimodal discourse analysis (image, sound and gestures), sociolinguistics, social semiotics, among several others (see van Dijk, 2015; for a general review; and Traynor, 2006 for a review of nursing studies).

- Authors were inquired regarding ethical misconduct, they
 have claimed that in the time of pandemics no ethical approval
 is necessary, which is against the WHO guidelines on ethical
 dimension to be followed in the time of the pandemic.
- In between again they changed their agenda and mentioned that for a single case it is not necessary to take any kind of ethical approval.
- According to the principles of bioethics, there should be an informed consent with information necessary for the patients and even researchers should mention that what kind of benefits basically the patients can gain from this research process.
- According to the Helsinki declaration, the person whose biological samples have been used for research should have full rights to get information about the research process. (For e.g, specific research methods, the purpose of the study, the sources of the funding and other information related to the analysis).

- Expressing the ethical concern, Microbiology resource announcement has mentioned that it will follow ethical guidelines according to the Helsinki declaration.
- It has further specified that there should be the declaration of funding sources, institutional affiliations and clarifications regarding conflicts of interest.
- In contrast, apart from mentioning institutional affiliations of the authors, there was no evidence of funding sources and conflicts of interests mentioned in this journal which means the journal itself has violated the rules of the Helsinki declaration.

- Among the 15 authors of this article, 9 of them are non-Nepalese authors. The first author of this article mentioned that it is not collaboration in an ideal sense, he admitted that they have just sent a sample and that only they were informed about the gene sequencing process.
- Apart from two authors who are directly involved in the WHO
 reference laboratory placed at the University of Hongkong, the
 first author of this article is unaware about the process how
 other seven non-Nepali authors are popped out on the article.
- Chief of the epidemiology department has kept his professor's name in that article without direct involvement in the process of gene sequencing.
- Regarding the involvement of remaining others from the London University, University of Colombia and Nagasaki Universities, first author of this article has mentioned that he is also not aware of the process of involvement.

- In the context of Nepal, concerning individuals whose samples have been taken for the purpose of COVID 19 testing, the effects and results of the process are completely unknown.
- After this controversy arose, the NHRC followed up the individuals.
 However, it is mentioned that researchers have not taken any consent before sending the biological sample for gene sequencing.
- Since more than 40 researches have taken ethical approval to process and conduct the research on different dynamics of COVID 19, this particular process of gene sequencing has seriously violated the ethical principles developed by the Nepal health research council.

 According to The eight principles of the Data Protection Act 1998, personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.

- After some time, a clarification meeting was held in the ministry of health, the director of Nepal public health laboratory(NPHL) has mentioned that NHRC "does not deserve" any legal status to ask any kind of clarification.
- In addition, chief of epidemiology department who is one of the six Nepali authors also mentioned that no need to ask anyone better they prefer to continue their work in silence.
- The first author of this journal has mentioned that rather than celebrating this success as a victory for Nepali scientists becoming successful to publish in the worldclass journal, instead, the way NHRC is raising ethical issues is utterly discouraging and demotivating for the medical researchers.

- In this case, most of the bioethical principles which are related to the use of genetic resources have been seriously violated by those people who themselves are responsible to follow the ethical guidelines developed by NHRC.
- One of the authors of this paper is a director of NPHL and also an important member of the monitoring committee in Nepal health research council.
- After NHRC's Inquiry mail to the journal, authors have replied that since NPHL itself is an autonomous body no need to follow any ethical approval process.

A meta ethical inquiry

- Here the question arises, is it ethical to interpret the "wrongs" done by morally right person as "rights"?
- Or on the flip side, we should raise serious ethical concerns following the deontological position taken by the state agency.
- Here, I like to question the nature of power and the level of epistemic ignorance which has directly created the condition of epistemic injustice.
- This epistemic injustice is a by-product of epistemic ignorance of biomedical power those are operating to justify their teleological position.

A meta ethical inquiry

- Nonetheless, this process of gene sequencing can be interpreted from the lens of patient centred deontology versus agent centred deontological position, where patients' right's and autonomy has been undermined and remained 'utterly silenced' and the benefits of the authors or agents became more prominent in the form of academic publications.
- In this particular case, the way biomedical power has louder its standpoint with support of family-legal power is yet another form of power which has been operational to justify the teleological or consequentialist position of the authors.

A meta ethical inquiry

- Moreover, in this case, very nature of biomedical power should be questioned, which has overtly tried to justify its position by saying that state's ethical body has no rights to make any kind of inquiry.
- Rather than seeing this particular case just as a violation of different kinds of national and international ethical guidelines, the teleological position has been overtly taken against the deontological position in conjunction with bureaucratic power and biomedical power.
- Eventually, this event resulted in the filing of case against the NHRC at the supreme court of Nepal.

Thank you for your active listening,
 Questions, Comments, Suggestions and
 Criticism are kindly welcome.