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Leprosy Sufferers and Gramscian Perspective Challenges for Social Work Professionals

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Abstract: ***After the elimination of leprosy from public health index in India, leprosy sufferers have being facing acute discrimination in different contexts like social, economic, cultural, political and environmental ones. The 'Institutionalized Discrimination' has been the prime concern for the leprosy sufferers, results in making them 'Second Class Citizen' practically that leads to cultivation in cyclic deprivation for them and was restricted to 'Social Exclusive Community'. The prime objective of this study is to explore the ontological, epistemological and methodological issues in re-examining the discriminatory practices against leprosy sufferers in socio-economic and political structure. This study is based on primary data from twenty respondents collected through qualitative approach with purposive sampling design (include in-depth interviews with formal discussions) from Motinagar Ashram, Dehradun; Uttarakhand, India. One of the major findings projected that after the elimination of leprosy from public health concern, policy makers have less attention towards the sustainable welfare of affected people that leads to promoting luxuriant growth of inequality against leprosy sufferers in accessing socio-economic resources from the community. This study concluded that effective community-based intervention is needed for the holistic development of the leprosy sufferers in sustainable environment.***

Keywords: Leprosy Institutionalized Discrimination, Socially Exclusive Community and Gramscian Notion.

I. INTRODUCTION

Leprosy as a neglected tropical disease is one of the major concern for the social workers to deal with it. To understand the socio-cultural complex realities of Leprosy, one has to understand the dynamic connotative meaning of leprosy which is deliberately associated with it and its consequences on affected people. Connotatively, leprosy also known as Hansen's disease, is not just a chronic infectious disease caused by *Mycobacterium Leprae* but also deliberately associated with the stigmatized perception that it is kindred to 'bad blood' and is caused by 'curse of God' due to which, affected people have being facing acute discrimination in social, economic, cultural, political and environmental context and this leads to promotion of unsustainable environment in every hemisphere for them. After the elimination of leprosy form the public health index of India in 2005 (*The Hindu*, 2018, February 4th), leprosy sufferers are more vulnerable and excluded for the mainstream society and it affects their socio-economic and political sustainability. Out of 1, 27,558 total cases of leprosy globally, 92% of the cases are found in two South East Asian Countries i.e. India (120334 Cases) and Indonesia (17017 Cases), in 2020 (World Health Organization, 2021). To understand the complexity of the problems in the matter under discussion, there is a need to critically evaluate the structural-functional issues of the government and civil society's welfare intervention process to eradicate the discriminatory practices towards leprosy sufferers.

From the theoretical perspective, Leprosy as a sensitive issue associated with Medical Social workers to curtail the psycho-social and emotional challenges which leprosy sufferers have frequently experienced. To eradicate the stigma attached with any concept or issue, firstly there is a surely need to understand the roots from where that concept or issue is emerged. With that in mind, firstly there is a need to provide a substitution of 'derogatory term' to eradicate the stigma attached with this disease. To overcome this problem, the United Nations, in its Resolution A/HRC/15/30 (Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members), under point (of the guidelines) has clearly restricted the term 'leper' for the leprosy sufferers.

> *"the state should remove discriminatory language, including the derogatory use of the world 'leper', or its equivalent in any language or dialect from government publication"* (Human Rights Council, 2010, August 12th).

Despite of many different welfare schemes, policies, programmes and guidelines implemented by government to provide affordable, accountable and acceptable environment to the leprosy sufferers, they still faced 'institutionalized discrimination' in different contexts.

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II. CONTEXT OF DISCRIMINATION WITH LEPROSY SUFFERERS

Leprosy has been associated with negative intentions ever since the commencement and almost all the religions portray leprosy in a destructive way. Leprosy has been acknowledged in classical Hindu law as the manifestation of sin that was done by an affected person in his previous life and now he is being punished for his past deeds in this life (Mehala, 2018). She had given some examples of traditional terminologies used for the leprosy noted that during 1400 B.C. leprosy was referred as '*Kustha'* which means 'eating away', mentioned in the ancient Vedic writing. These biased traditional terminologies uplift the luxuriant growth of stigma and inequality against the leprosy sufferers in the Indian society. Still in contemporary scenario, these biased terminologies have direct impact on the mindset of many unaware people that leads to cultivation of discriminatory environment against the leprosy sufferers. To eradicate the discrimination and provide an equal opportunity with equity to the leprosy sufferers, the theme of World Leprosy day 2022 is "United for Dignity" to propagate the dignity for those people who experienced Leprosy is selected. Practically, in contemporary scenario it is important to understand the different discriminatory contexts associated with leprosy sufferers that need to be extinct, are mentioned below:

A. Socio-cultural Context

Due to lack of proper awareness and knowledge among the common people, leprosy is riddled with stigma since at least 4000 B.C. (The Economic Times, 2020, July 27th). Proliferation of stigma with this 'neglected tropical disease' leads to empower the unsustainable situations like socially excluded from mainstream society, ostracized and limited on availing community resources, denial from proper formal education, employment, exclusion from social gatherings and often loose to freedom of choice in marriage for the affected people. Such practices violate the fundamental and human rights of an individual. Because of 'culture of fear' associated with the disease, the leprosy sufferers have been subjected to inhuman treatment and socially excluded by the society throughout the recorded history whether in Europe, Asia, Africa or the New World (Dols,1983). These discriminatory practices are still propagated because of invisible and sometimes unauthorized institutional support from religious groups, community members and social institutions.

To eradicate the socio-cultural discrimination, first and foremost important step is annihilation of the misconceptions and myths attached with this disease through proper channelization of awareness campaign at grass root level. Secondary, to change the views and attitude towards the disease, there is a need of proper involvement of the religious leaders in those welfare activities that are focused on elimination of stigma attached with the disease. Involvement of religious leaders is necessary because the historical background of this disease reflect the religious stigmatized perception like 'curse of God' and 'bad blood' towards leprosy. In many places researcher found that people throw their garbage close to the leprosy colonies without realizing that people living there are also humans and they also need a clean and hygienic environment. To eradicate the stigma associated with any issue, perception or context, there is always a need of scientific and practical support from the society.

B. =

C. Political Context

Political participation for any community, society, group or individual is one of the most important elements to develop and express their opinion in front of others. In a democratic country, everyone has the right to contest and participate in political process but there are some states in India like Rajasthan prohibit leprosy patients from running in local elections and exclude them from employment opportunities and other socio-political benefits (The *Hindu*, 2018, February 4th). Telangana has three different such laws like the Greater Hyderabad Municipal Corporation Act, 1955 which excludes an individual suffering from leprosy from being nominated as a member (The Times of India, 2021, February 16th). Neighboring Andhra Pradesh has also practiced such laws (The ToI, 2021, February 16th). Exclusion form the political affiliation for a particular group like leprosy affected people leads to cultivate a barrier for them to make their own decisions and share their problems with the authority. This type of socio-political barrier directly attacked the sustainability of that particular community. Due to this political exclusion, makes their own 'Socially Excluded Community' not by choice but by circumstances. Somehow, the state is responsible for the exclusion of leprosy sufferers in political sphere that propagates the 'organized discrimination' with them.

To eliminate the political discrimination with the leprosy sufferers, there is a need of affirmative action based on right-based approach to spread the awareness at grass root level like *Zila Parishad* (i.e. district level), Block *Samiti* (i.e. community level) and *Gram Panchayat* (i.e. village level) and also among the leprosy sufferers about their political rights which is given and protected by the constitution of India like the Convention on the Rights of Persons with Disabilities (CRPD), Article 29 (on participation in political and public life) mandates that "States parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others" (The Leprosy Mission Trust of India, 2020).

There are numerous non-government organizations like The Leprosy Mission Trust of India (TLMTI) working in this sector through providing awareness with right-based approach by providing linkages between Self-help Groups and DPOs to develop the different skills and abilities among leprosy sufferers that are mandatory desirable to participate in political process like public speaking, problem solving skills and campaigning. After these affirmative rigorous efforts by different organizations like The Leprosy Mission Trust of India at grass root level in some states like Chhattisgarh, Maharashtra and Uttar Pradesh over 190 leprosy affected people contested elections to Panchayati Raj Institutions in which 83 were won; other 54 leprosy affected people were nominated to various Panchayat sub-committees (The Leprosy Mission Trust of India, 2020).

D. Economic Context

Economic discrimination is closely related to socio-cultural discrimination. Rather, it would be better to say that economic discrimination begins with socio-cultural discrimination. If such a sustainable framework developed where everyone get an equal opportunity to share power and resources without any social disability and also that removes socio-cultural discrimination from the grassroots level then economic discrimination will be easy to encounter and eliminate it in that particular society.

From the past two years, during the Coronavirus pandemic (Covid- 19), leprosy sufferers and their families faced socio-economic upheaval that affects their daily life critically (Perappadan, 2022). Many of the mandatory preventive steps taken by the government to control the spread of virus in the country like lockdowns have made much harder scenario for the marginalized communities in terms of their income generating opportunities. Likewise leprosy sufferers faced diabolic situations in terms of accessing the medical treatment, deprivation in financial opportunities and aggravate their deprivation that they already faced.

To reduce this situational deprivation caused by pandemic, Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination launched an awareness campaign in August 2021 called “Don’t forget leprosy” (WHO, 2022, January 10th) with an ambitious step towards ensuring the financial problems of the leprosy sufferers and they will not neglected during pandemic and also his foundation namely Sasakawa- India Leprosy Relief Foundation gives micro-finances to the leprosy patients for their better economic independency.

It is also very important to understand that just as socio-cultural discrimination is an ‘institutionalized discrimination’, in the same way, economic discrimination is an ‘organized discrimination’. For example: many employers used some articles of different acts against the leprosy sufferers to ax them from their jobs like *Section 2(o)(oo)(c)* of the Industrial Disputes Act, 1947 that allows the termination of employment of the persons on certain ground including a person is affected by a communicable disease. Once a person is diagnosed with Leprosy (it doesn't matter that he/ she are completely cured) is axed from his/her job.

To ensure the economic sustainability of the leprosy sufferers, there is need of advocacy on rejuvenating those acts that have some flaws and develop a proper structural mechanism to maintain and administer the transparency of the employers towards their employees, especially for those who are marginalized. This transparency towards employees will be ensured only through the right based approach. There is need of constructive environment inside and outside the institutions and provision of decision making power should be ensured by the employers among their employees through policy making. Involvement of marginalized people like leprosy sufferers in management and human resource policies will ensure the accountability of the leprosy sufferers’ employment opportunities.

III. TOWARDS THEORETICAL INTERFERENCE: GRAMSCIAN NOTION

To understand the theoretical perspective on the Leprosy; Gramscian perspective of ‘popular common sense’ is used in this study. To generate a practical framework to annihilate the biased or stigmatized socio-cultural perspective associated behind the term or concept, firstly there is need to understand that why people adopt that perspective in their daily life situations and how the attitude or values are generated by the people towards that term or concept. Everyone have their own intellectuality to ‘understand the world’ and its related concepts. Some of the understanding are generated because of past experiences, or imposed by others like elders and outsiders on the name of Religio-cultural practices and are accepted and practiced uncritically (Forgacs, 2000). In perspective of this study, it is called as ‘common sense’ what Gramsci constitute. ‘Common sense’ in general understanding is a general philosophy that actually relates a coherent worldview to your own life and place in society. Gramsci provides a critical philosophy of common sense that:

> *“Which is the “philosophy of non-philosophers” or in other words the conception of the world which is uncritically absorbed by the various social and cultural environments in which the moral individuality of the average man is developed. Common sense is not a single unique conception, identical in time and space. It is the “folklore” of the philosophy, and, like folklore, it takes countless different forms”* (Afsana & Shahid, 2018, p. 46).

Thus, the popular common sense is responsible for contributing in cultivation of biased socio-cultural and religious practices and norms governing these practices as normal and natural that leads to upliftment of relative deprivation in the society. The popular common sense is the sedimentation of ideas over the years due to distinctive reasons, whether it is biased or unbiased and hence, it reflects the specific but common community attitude of people towards leprosy and its affected people. Thus the popular common sense repertoire of Gramscian Notion on Leprosy is a repository and reflection of popular perception on leprosy and affiliated practices, the situations which are faced by the affected people and because of stigma attached with the disease, it concealed as 'open fear' under the culture of hidden fear. It is easy to understand that stigmatized words are used and accompanied by the proverbs, idioms, phases, stories and other forms of narrations to reflect their own emotions and experiences in the community. In this study the popular common sense repertoire lens is used in understanding and mapping the plethora of discriminatory practices against leprosy sufferers and the socio-cultural and religious norms governing the same. Through the Table-1, it is easy to understand the ontology, epistemology, theoretical perspective and methodology for understanding the context of discrimination against the leprosy sufferers:

Table 1: Ontology, Epistemology, Theoretical Perspective and Methodology on Understanding Leprosy

Philosophy/ Perspective	Orientation/ Approach	Description
Ontology	Relativism	Leprosy is not only attached with singular perspective that it is an infectious disease caused by Mycobacterium Leprae but also embedded in multiple socio-cultural and religious realities like curse of God, bad blood, sinner soul etc.
Epistemology	Social Constructionism	Leprosy as historic reality associated with conduct of bad behaviour and over the period of time, people attached different biased perspectives on the basis of their sedimentation of ideas, attitudes and beliefs that leads to cultivation of socio-economic and political exclusion, ostracized and making affected people as 'Second Class Citizen'.
Theoretical Perspective	Critical Theory	Popular Common Sense Repertoire of Gramscian Notion is used as an effective theoretical lens to explore and understand the institutionalization of discriminatory practices with the help of biased laws and made to appear as normal and natural in specific social, political, economic and cultural context that propagated the relative deprivation against Leprosy Sufferers.
Methodology	Qualitative	Stock Narratives, In-depth Interviews and Focus Group Discussion

IV. LEPROSY AND POPULAR COMMON SENSE REPERTOIRE

According to Perappadan (2022), due to Covid-19 pandemic leading to social distancing and lockdowns caused a fall of 62.5% in the detection of active leprosy cases between April to September 2020. During this pandemic situation, where the whole country is trying to avoid the disease, on the other hand, India is facing an economic deflation (might be the reasons are hidden fluctuated or because of political corruption) because of which leprosy sufferers faced diabolic situations in their everyday routine like lack of monitoring in regular medical needs, limitations on accessing partial livelihood opportunities that taught us, the most important was, perhaps, the fact that the 'vulnerable population' is not a homogenous entity. This pandemic demonstrated how vulnerability with complex intersection of different social variables like poverty, disability, stigma, exclusion, etc. affects different vulnerable group differently. This substandard condition is not something new for them in fact, in antiquity, people believed to have contracted leprosy patients of their family members, were forcibly thrown out of home and from their native places and ostracized from their own property and settlements and demonstrate them as a threat to rest of the society. The oppression not end here, in medieval Europe, accused leprosy victims were executed by burning, crowning, or live burial (Raju, 2000).

Due to 'culture of fear' attached with the leprosy and its affected people in social hemisphere there are lots of problem occurred as consequence like ostracism, marginalization, dehabilitation, destitution etc. Just to prevent them from these resultant problems, suspected cases were not disclosed their disease to the family members, friends, villagers, etc. and not take proper consultation from any doctor.

Once the deformities set in, the affected person suffers loss of occupational resources, denial from social gathering, forced to 'leprosy endogamous marriage', etc. and not only the affected person suffer but the family also suffers from economic, social and psychological problems.

From an economic perspective, leprosy as a nerve disease association leads to nerve damage causes deformity and disability. For a person who is indulged in physical labour, disability means to him/her; a threat to economic survival like loss of physical productivity resulting in economic deprivation and often leading to destitution (Mahanasundaram, 1994).

Leprosy has different negative connotations in different languages and it is used to demonstrate the negative activities done by a person in their past life and it's been a shameful action for the society to support that affected person. In India, Leprosy is termed as *'Maharog'* which means 'a great disease' that is completely unaccepted in the society (Ghimire & Madan, 2003). In ancient Vedic Writings Leprosy was referred as *"kustha"* as far back as 1400 B.C. and its prevention is mentioned in the Law of Manu. A well explained description of Leprosy and its treatment was written by *Sushruta;* an eminent Indian Surgeon in his book *Sushruta Samhita* (Ghimire & Madan, 2003). The Leprosy Mission Trust of India (2022) mentioned that different religions have different opinion about the leprosy because, in past, Multi Drug Therapy was not introduced for a proper treatment that meant to lifelong disability and disfigurement and living in isolation and disgrace. According to the trust:

1) In Hinduism, the Manu Smriti (circa 1500 BC) states that; if family are affected by Leprosy, then that family was excluded from getting married to any other normal family.

2) In Christianity, the Holy Bible has several references (especially the Book of Leviticus, chapter 13) that Leprosy is disease which referred to as a divine punishment for sins.

3) In Islam, commands the faithful to "Flee from the 'leper' as you would flee from a lion," as leprosy is chronic infectious communicable disease that is transmitted quickly and kills the one who affected from it.

4) In Buddhism, call leprosy a 'karmic' disease (A karmic disease is considered a punishment for sins in one's past lives).

To a large extent, to stay away from a leprosy patient because of communicable nature of the disease, is accepted when there was no proper complete cure for this disease but now our medical field has developed so much and it is completely curable disease. The only thing we need and practiced now is to completely change our minds towards understanding and studying leprosy as a disease. There is surely need of treating people with leprosy sufferers as their own and helping them to have a better and sustainable life. This is a long journey in which half of the journey is completed through together conscious efforts by different concerned stakeholders and administrations and half is yet to be completed. According to the government of India, leprosy is successfully eliminated from India in 2005 but only eradicating the disease justifies the concept of 'sustainable relief' for the leprosy sufferers, is it so? No, rather it is the prime responsibility of all concern stakeholders that they must work together to give them an equity based platform where leprosy sufferers can stand up and fight for their rights under the parasol of constitutional protective sheds and in every way they can accommodate all the luxuries as per their need that all other citizens used to fulfill their basic needs and to maintain their sustainable quality of life.

V. STATUS OF LEPROSY IN INDIA

To eradicate the leprosy from its root, it is important to stop its transmission process first and then need to move towards zero new cases. To make it practical, World Health Organization has introduced his new strategy in more than 100 countries with an aim to reduce the disease burden in the countries by 2030 (WHO, 2021). However, still there are some countries where socio-cultural practices dominated over medical treatment and stigmatized perception attached with the disease leads to high rate in leprosy cases. Like in India, due to fear of socio- economic and political lose attached with the disease; affected people hide themselves from the society and due to this, the disease starts spreading more. To eradicate the fear and stigma attached with the disease and generate awareness among the society members; in 2018, government of India was conducted a campaign named as "SPARSH Leprosy Awareness Campaign" from 30th January to 13th February nationwide.

Another reason is undetected cases, such as leprosy, if it is in children, then it is very difficult to find out the affected one that also leads to increment in cases. The ministry official said that:

> *"India now relies on voluntary reporting, which may lead to many cases being detected late or people getting treated after disability has set in"* (Sharma, 2017).

The National Leprosy Eradication Programme, 1983 was one of the most effective programmes launched by government of India under the Ministry of Health and Family Welfare to eradicate leprosy with the help of trained health workers from the country through proper regulation of treatment, intensified health education and public awareness through different means of communication and by providing appropriate medical rehabilitation. Till, 31st March 2018, India had attained the level of leprosy

elimination i.e. prevalence rate of less than 1 case per 10000 population in 572 districts (81.13%) out of total 705 districts and in 2020 it was 0.57 cases per 10000 population (National Health Programme, 2021). However, it is also important to accept that India has maximum number of leprosy sufferers who are disabled due to this disease and 57% of the new cases are worldwide are diagnosed in India (Agnani, 2022).

For the permanent settlement of Leprosy sufferers because they are ostracized from their own family members and society due to 'fear of contracting' and 'stigmatized perception' towards leprosy; government of India implemented a scheme namely 'Rehabilitation Centers for Leprosy Affected People' in 1981. Under this scheme, leprosy sufferers get permanent residential places in Delhi. Later on, this scheme was extended to 1993. Under this scheme leprosy sufferers get basic necessities to run their life like dry ration, clothing, bedding, medicines etc. Later on, cash amount of Rs. 300/- was also given to them as a financial support and now at present, it is Rs. 1800/- per month but still a questionable on the sustainability of the leprosy sufferers where the inflation has increased so much that even a common man unable to maintained his entire month expenditure with that amount.

From the critico-analytical perspective (perspective based on the critical understanding of the concept or issue and on that understanding provide an analytical overview for in-depth understanding of the concept or issue), it would be easy to estimate that all the government welfare interventions that have been implemented for the leprosy sufferers are only able to meet only few of daily needs. But in terms of their sustainability, the Government of India is still a long way off. Providing two loaves of bread to the needy is not a sign of sustainability rather to enable him/her self- sufficient to earn that two loaves of bread on his/her own strength and access all the luxuries and resources that an individual enjoyed. Somehow, these welfare policies make them more disabled that leads to 'creation of dependent environment' (like dependency on non-government organizations' welfare schemes, dependency on charities and dependency on government welfare schemes). To annihilate this 'dependent environment', there is surely need of involvement of leprosy sufferers in decision making process and action oriented programmes that are implemented for their welfare.

To create a sustainable environment for leprosy sufferers; from this point of view, there is need of bipartite support i.e. government and non-government organizations. In the beginning stage, the government should responsible to provide them financial assistance on a small scale so that they can start their own small businesses and the role of non-government organizations will be to provide a linkage between their business and market, so that they can run their business smoothly in a sustainable manner.

To understand the epistemology of leprosy, there is a need to comprehend the socio-cultural and political determinants of the disease. The socio-cultural determinants associated with the leprosy are one of the prime reasons to make this disease more critical in other hemispheres. A small unnoticed patch on an individual, once medically diagnosed as leprosy, envelop the patient with the cumulative feeling of helplessness, shame and dependency (Gokhale, 1980, p. 56). This study therefore, specially reflects the discrimination faced by the leprosy sufferers in different contexts and the relative importance of popular common-sense repertoire of Granscian notion in planning and proposing effective community-based interventions framed on right based approach by social work professionals to eliminate the challenges that are faced by them during field work with leprosy sufferers.

VI. RESEARCH METHODOLOGY

The government of India has taken various preventive measures to improve the medical conditions of leprosy sufferers and rehabilitate them, that lead to elimination of leprosy from public health index in the country today. But leprosy; associated with stigmatized perception, create more difficulties for a patient for his sustainable survival in the society in post-treatment stage. The patient suffers more from the society's biased perception then the disease itself. Due to public anxiety about this Hansen's disease, patients were deprived from their own basic rights like denied the right to vote, restricted in accessing the resources and often forbidden from contacting their own parents and children (Fessler, 2020). Socio-economic and political discrimination has become so ingrained in their lives that none of them were longer realize that they are being discriminated in the society and what's even more surprised is that they've accustomed used to it that leads to cultivation of relative deprivation.

Researcher also came across the same experience of relative deprivation during discussion with the respondents during research process. The data was being collected for the research purpose on Leprosy Sufferers and their distinctive discriminatory contexts with selective purposive sampling between the age group of 18-50 years who are completely cured and come under the category of Grade-0 (i.e. absence of disability (no anesthesia) and no visible damage or deformities on eyes, hands and feet) and Grade-1(i.e. loss of protective sensibility in the eyes, hands or feet, but no visible damage or deformities) under tuberculoid leprosy as per the categories defined by World Health Organization for physical disability in Leprosy and others are excluded. A total number of twenty study respondents were selected on the basis of equal ratio with gender division lived in Motinagar Ashram, Dehradun. The primary data was collected through in-depth interviews (IDIs) along with informal discussions to assess the consequences of discriminatory practices in different contexts on the sustainability of leprosy sufferers.

During the in-depth interviews, respondents were active in sharing their past lived experiences with the researcher but they were quite articulated in terms of sharing their experiences regarding affordability, accessibility and availability of resources provided by the government organizations for them in post treatment stage for maintaining their sustainability. Most of the respondents preferred to remain silent and some respondents sarcastically agreed to the services provided by the government for their welfare. This meaningful silence and sarcastically agreement prompted the researcher to probe the respondents' experiences that they go through in their society. When research is conducted on such sensitive issues that are directly associated with socio-cultural complex realities and the researcher trying to critically analyzed the structural and functional mechanism of an organization on which our respondents are totally depend to access and afford their daily basic needs then in that case it is challenging for the researcher to obtained meaningful data in such situations. With this aspect in mind, the whole approach of studying the leprosy and intervening challenges in Social Work perspective was reinvestigated and revaluated in this research. Inconsequence, it is merged out that the popular common sense repertoire is full of experiences shared by the respondents on discriminatory practices faced by the leprosy sufferers in their daily life. The one that need to be considered the most important perspective in understanding the level of discrimination and its consequences is that while the respondents were sharing their experiences with the researcher in popular common sense perceptions this also make them aware about their own rights and how they were become the victims of relative deprivation unconsciously? This calls for understanding 'popular common sense repertoire' of Granscian Notion as a theoretical lens and practical tool for study and intervening challenges with leprosy in social work context. There is also a surely need to revitalize the ontology, epistemology and methodology for approaching and studying the leprosy as a socio-cultural phenomenon.

VII. REVITALIZING ONTOLOGY, EPISTEMOLOGY, THEORY AND METHODOLOGY ON LEPROSY

The experiences undertaken during data collection process on socio-economic and political discrimination against the leprosy sufferers reveal some new aspects. For better understanding about these new aspects, the popular common sense repertoire on leprosy argued for revitalizing leprosy from a different ontological, epistemological and methodological point of view. While the canvass of the terms ontology, epistemology and methodology has large historical and philosophical foundations (Afsana & Shahid, 2018) but there is a need to restrict this discussion so that research can better articulate his perspective and present a self-explained outline of the problem.

A. Ontological Perspective

According to Rawnsley (1998), ontologies are theories of what exists and claims regarding the nature and structure of being. It defines the primary or basic philosophy (i.e. metaphysics) that concerned with describing the ultimate nature of things as they are. Precisely, ontology attains knowledge about that exists in the human world and it locates in explaining the very nature of reality (Afsana & Shahid, 2018). To understand the ontological perspective of leprosy which is directly proportionate to socio-religious based stigmatized perceptions like 'bad blood' and 'curse of God', relativism approach is required. Relativism argues that there is no reality beyond subjects and it exists as multiple and intangible mental constructions (Moon and Blackman, 2014).

B. Epistemological Perspective

Epistemology is used in conjunction with the phrase knowledge to encompass philosophical issues related to the origin and structure of knowledge (Moon and Blackman, 2014). To understand the epistemology of leprosy, firstly there a need to elaborate and critically assess the priori perspective associated with the leprosy. Basically priori is an intuitive and inherent knowledge obtained by analyzing concepts that are independent of experiences and sensory perceptions. Secondly, to normalize the priori perspective; there is need to shift from priori to posteriori tenets. Posteriori is a knowledge that is propositional or contingent based on empirical evidences that are obtained through sense experiences. Another dimension associated with leprosy is independent attachment of socio-cultural complex realties that propagate the stigma and myths with this neglected tropical disease. To know about this embedded dimension, social constructivism approach is used which contends that meaning is created from the logical interplay between the subject (i.e. society) and object (i.e. leprosy) and hence the subject constructs the reality and meaning of the object (Afsana & Shahid, 2018).

C. Theoretical Perspective

Theoretical perspective is one of the most important elements in reflecting the philosophical orientation of the research that guides the research. For a particular research, theoretical perspective emerges from the ontological and epistemological positioning of the research problem. Theoretical perspective extends from positivism to interpretive and critical theories (Afsana & Shahid, 2018).

From the theoretical perspective, to change the relative deprivational situation related to the leprosy that appears as normal and natural in socio-cultural context; critical theoretical approach is used that focused on power relations, critiques, assumptions and evolvements. A critical theory not only discusses historical facts and inherent dichotomies, but also seeks to change the situation (Afsana & Shahid, 2018).

D. Methodological Perspective

Methodologies are concerned with procedures based on scientific insight for yielding information that is sensible and acceptable. Methodology acts as a mediator of reality in promoting scientific goals within the philosophy of science (Rawnsley, 1998). Therefore, its scope can be broader as well as restrictive in practical perspective. It can be broader in the perspective to discriminate strengths and limitations of the true value of a method for developing knowledge characteristics in various scientific disciplines and restrictive as precision of measurement and mathematical analysis of data (Dancy & Sosa, 1992; Urmson & Ree, 1989). Thus, the methodological approach for this study is contingent to ontological, epistemological and theoretical perspective.

After the critico-analysis of this study, it emerges out that without understanding about the socio-cultural dimensions associated with leprosy; it's difficult to analyses the causes of discrimination with the affected people. Through cultural dimension, it is easy to develop a framework for the society to project health and disease, deformity and normality, life and death. The discrimination with any disease does not come into existence overnight; it takes a long process of undue socialization and invalid learning process. Thus it seems that ontologically, leprosy is not just a disease which is completely curable but it has socio-cultural complex realties which are associated with it from the very beginning stage and people ascribed different meaning over the period of time. To understand and explore these meanings connotatively in a sensible perspective, epistemologically, Social constructionist lens could be better approach. Through this approach it is easy to understand that society as a subject projected leprosy as an object; disease is caused by wrong deeds done by an affected person in his previous life due to which discriminatory practices are cultivated against leprosy sufferers. The popular common sense of Granscian notion seems to be helpful in not only understanding how these discriminatory practices are propagated that leads to relative deprivation become normalized against the leprosy sufferers in a particular social, cultural, political and economic context but it could also be accommodating in challenging those illegitimate and oppressive practices that motivate in building discriminatory platform against the sustainable development of leprosy sufferers and proposed counter hegemony (narratives). In proposing a scientific based theoretical perspective, critical theory could be helpful for social work professionals to understand the organized and institutionalized discriminatory realities. It is also supportive to work on changing the situation so that it could provide an emancipated platform for the leprosy sufferers. Resulting to the relativism ontology, social constructionist epistemology and critical theoretical perspective of popular common sense, the methodological approach is decided for this study. In order to explore and critical assessment of discriminatory practices and its consequences against leprosy sufferers; the qualitative approach seemed best suited in developing the narratives through oral history, in-depth interviews and focus group discussions.

VIII. DISCRIMINATORY PRACTICES AGAINST LEPROSY SUFFERERS OF MOTINAGAR ASHRAM

Motinagar Ashram situated in Haldwani district was established by the British Government in 1934, spread over 22 acre of land, and carved out of the Hathikal Forest as a home for the leprosy patients. At the time of establishment of this ashram, it had no place of residence and no connection with other people in nearby locality for emergency purpose. The reason for making this ashram in isolated geographical area was that people with leprosy could be isolated and excluded from the rest of the society because of lack of proper medical knowledge and complete cure about leprosy disease at that time and but now people are starting to aware themselves about this disease with the help of Accredited Social Health Activists (ASHA workers) and local doctors and to a large extent community people are looking leprosy as disease point of view which can be completely cured. This debarred settlement is just because of instinct deliberated presence and disinclined projection of fear, myths and misconception towards the disease; leprosy sufferers have been subjected to excluded from their psychological freedom and emotional development that leads to propagation of inhuman treatment against them and discarded by the society throughout the history (Raju, 2000). Now, there is a village situated in the area, which can be approached through the Bareilly Road from Haldwani, after a drive about nearly 7 km.

Throughout this research an important aspect has come to the fore which needs to be considered and critically analyzed. The traditional methods of studying leprosy and its relatable context of discrimination is limited to abolition of myths, misconceptions and stigma only that can be eradicated through proper channelization of awareness programmes in our country but these methods are not suitable and enough framed to develop a sustainable environment for the leprosy sufferers. Initially, to understand the nature of discrimination experienced by the leprosy sufferers, the questions on discrimination context were marked by reactive behaviour

towards the research and further, leprosy sufferers were got up after a while with asking a critical question to the research, "*tu kya mari roti ka faisla karega, jab na kar paiga to phir kya faida, ham pehle bhi dusron ke sahare pal rahe the aage bhi aise hi kat jawega.*" (Are you in a position to provide us food, when you will not be able to do then what is the benefit of all this, we were already bridging with the support of other and will continue to be like this) [IDI-3]. To eliminate this perception and taking as a challenge for the better development of the leprosy sufferers, there is surely need to revise and revisit the ontological, epistemological and methodological positioning in making sense of the intervention process in more positive outcome oriented with the leprosy sufferers. In consequence, popular common sense repertoire of Gramscian notion was used as a theoretical lens in projecting the theoretical perspective to understand and develop a sustainable framework for the elimination of the 'organized discrimination' with the support of different stakeholders. To project and narrate the popular common sense, leprosy sufferers were facilitated in in-depth interview (IDI). The amend approach generated critico- analytical results and a rich in-depth relatable narratives on popular common sense perception on associated discriminatory practices against leprosy affected people in community evolved that cultivate the relative deprivation among the leprosy sufferers. For better understanding and generate a sustainable framework, qualitative data analysis of this study is organized into three sections as mentioned below:

A. Problems Occurred in Pre Treatment Stage

Regarding the problems and discrimination faced by the leprosy sufferers in the pre-treatment stage; some open ended questions were asked to respond. Once the disease is detected, leprosy sufferers faced discrimination within their own family members, socially excluded by the neighbours and ostracized by their own society that generate extreme psychological and social problem for the affected people. Some case studies in this regard are mentioned below:

1) It is better not to tell about this disease; otherwise your own family members will force you to leave the house. They will not give you food even if you die of hunger. The house in which you have invest every single penny of your whole life is the same house that makes you feel like someone else's house just because you are affected with this disease. [IDI2]

2) When my children found out about my disease, they treated me very well at first; there was nothing regarding misbehaving or any type of torture. They explained to me politely that it is a communicable disease and need to treat. For the treatment purpose they take me here and promised me that once I will get complete cure, they will get me back to the home. Now, it been an around five years; no one call me and no one came to see me. I miss my home a lot. I went home once after I got well but I did not dare to step inside the house. What should I do and who should I take when they have already forgotten me and now whether I am or not in their life, it does not matter for them. [IDI6]

3) Son, as much as you have read and understood about this disease, it's just a few characteristics associated with it; the other extreme dark sheds are only explored by affected person in his life. The government provides us free medical treatment but what about freedom to be the part of mainstream? What about our freedom to access the general job opportunities that others are easily avail? From the day the disease is diagnosed, we are suddenly transformed from a human being into a burden that no one wants to carry on their shoulders. You can easily analyze here that, we are living a life of dependency; the significance of our decision was lost on the day when our acquaintances found out about our disease. I don't have that much courage; otherwise I would have been so mentally disturbed by this life that I would have committed suicide long ago. Until I came here to the ashram, I considered myself the lowest level of wicked person who has no status and value in this world and even here our life is just where there was no reason to live; at least I have some friends with same mentality and they are the reasons for me to live my life. [IDI7]

B. Problems Occurred in During Treatment Stage

To understand the complex situations faced by the leprosy sufferers during their treatment in different contexts like social, political and economic one; some in-depth open ended questions were asked to the respondents. During the treatment process one of the major problems faced by the leprosy sufferers is lack of financial support from any context. Because of socio-stigmatized perception attached with this disease and institutionally, wrong use of acts that are develop and maintained by our constitution, they are retrenched form their jobs and if leprosy sufferers run a small business then in that case, they faced social exclusion from their own society. This practice of ostracism is not limited to the affected person; it creates a socially excluded environment for the whole family. The patient's children get out from their school or get tortured by the administration to take back their names from the school. All these practices forced affected people to reconstruct their own society which is completely "Socially Excluded Society". Government provide them space to build their own colonies but this welfare practice again propagate the stigma and social exclusion for them and build a huge gap of social acceptance between the mainstream citizens and leprosy sufferers. Some case studies in this regard are mentioned below:

1) We get medicine on time but how do we feed our family. I was working on the daily wage; contractor fired me because of my disease with an excuse that the others will also get in contact with this disease. He also assured me that he will take me back in the job, once I get completely cured. Now tell me, brother, my daily income was 800 rupees and I used to run my house with that. My family consists of 4 members including me, my wife and two small children. Tell me, which father would dare to see them hungry? This illness forced my wife to work. I have so many dreams I want my children to learn in some reputed schools. I thought a lot but this disease took away all my dreams. The wife also has to go to out of the village to work because no one in the village was given her a job. When she leaves and came back to home, she always covered her face because if anyone recognizes her, she will be kicked out from where she works, and again our kids will have to sleep hungry.[IDI1]
2) When my illness was confirmed, first of all my family members separated me and took possession of my all property and then unfortunately with the help of my friend, I came here and start my treatment but during the treatment my financial condition was bad that even I couldn't buy a single sweet of my own choice. I think the government made our treatment free but at the same time it is much more helpful for us that government should initiate some steps for us to make our financial condition strong especially during the treatment period so that at least we can earn some money to fulfill our small needs. During the treatment, my condition was like sometimes I have begged for paying the travelling charges for doing my check-up. I have no interest in begging, I used to earn and eat with my hard work but now look at my situation, I am completely depend on this trust for everything. [IDI3]
3) During treatment we have to deal with two complex situations, one from this ignorant society's perception for us and the other from instinct psychological and mental stress. We are so weakened by society's stigmatized perception towards us that we lose our self-confidence. At one point, I began to wonder that why I am getting this treatment, even though the situation would never be the same as before. Will my family adopt me or not, my friends will sit with me in social gatherings like before or not, I will be able to get my job again or not, will anyone wants to get married with me or not and likewise I faced and feel lots of confused situations in my mind . We can tackle that situation which is in front of us but how do we come up with the situation that is going on inside us? I have handled myself with great difficulty. I have handled myself with great difficulty and then I went and sat in front of you today and talking to you. We will get our treatment, we will take care of ourselves and we will fill our stomachs by doing something but it's a request to the people of this society that at least consider us human beings and if you cannot sympathize with us then at least do not abuse us. [IDI20]

C. *Problems Occurred in Post Treatment Stage*

To study the different aspects of leprosy sufferers in context of discrimination faced by them in post treatment stage in different hemispheres like social, political, economic and environmental one; some open ended questions were asked with the respondents during the in-depth interview with them. In post treatment stage, leprosy sufferers faced financial insecurity that leads to cultivation of deprivative environment for them in which they are forced for begging and rack picking, just to fulfill their basic needs. In Indian context, this is one of the most imperative challenges for the government and civil societies to create a sustainable economic framework for the leprosy sufferers under the category of Grade 0 and Grade 1 with minor deformities (as mentioned in methods) to access job opportunities, who are completely cured and in condition to do work. Some case studies in this regard are mentioned below:

1) I had dreamt of doing a job after finishing my studies but when I see my affected legs, I just forget about the studies. Even I didn't have money to study and then people were asking about this disease and making comments and it really made me depressed. Because of stigma attached with this disease, diagnosis for this disease is just like a death sentence for the affected person. Even we are completely cured, we still not accepted in the mainstream society just because of our deformative body. I am very much passionate to do work but no one wants to give me a job just. My request to all is that please provide us an environment where we can work without any stigmatized perception towards our disease. [IDI17]
2) Leprosy itself spreads conditions for poverty. Firstly, we were only allowed to settle in leprosy colonies from where the discriminatory perceptions attached with our identities. Then after settlement we were in absolute dependency on the charities and donations and there is no means of earning for us except begging and rack picking. Because of our deformative bodies even we were not allowed to be a part of prostitution. This is our reality. Whatever we have in the past, whatever we achieved in the life that doesn't matter at all, once the leprosy tag is attached with anyone; he/she is just a subject of discrimination, stigma, displacement, desperation and depression. I haven't found any job opportunities from past five years, desperately I need it but there is nothing in my hand even I have tried a lot in different places but in return I just got rejections and few drops of tears in my eyes to see my terrible sense of powerlessness and helplessness. [IDI13]

3) Social Taboos makes our life difficult. My parents were affected by leprosy and my in-laws are also affected by leprosy. I have been living around people with leprosy since childhood. So, I understand the pain, discrimination and the ill treatment faced by these people and I am also victimized for the same. I have tried for 4 years in different companies for getting job but unfortunately I didn't even get a single job. This socio-economic discrimination make us unemployed and dependable on others charity. The only source of income for us is begging. You have already visited our homes and you can easily understand that we have a very less space in which we have to do our daily needs like bathing, cooking and space for rest. I have nothing from government side except a pension card on the name of economic security and this is also not accessible for every one because it was started in 1994 and after a year, no new pension card was issued. Why would anyone give us a job when they don't even like to see us? [IDI20]

4) We are surviving through begging. After getting the confirmation about my disease, I was fired from my job, my family members were ejected me from my home, my friends were abandoned me. That time, situation was so tough for me that it was difficult to me to stay in the village. Here I have no proper facility of livelihood and there is no government intervention for our development, till today, I am survived through begging. You can easily analyze our pathetic condition, there no proper facility of electricity and water supply. Here we don't have our own lands and houses; only thing we have is these huts in which we faced many problems during winter and rainy season. If you people think that through providing us medical treatment, you can easily eliminate stigma, discrimination and other problems associated with us, then you were absolutely wrong. To eradicate this unorganized environment attached with us, you need to provide us proper sustainable livelihood mechanism where we can earn some money and bear our expenses so that we do not have to beg and we also have earn some respect in society. [IDI10]

Thus, all the above narratives thematically analyzed the three important contexts that need to be in prime consideration;

a) Need for change in socio- cultural perspective towards disease,
b) Strengthening process on functional mechanism in terms of implementation of government welfare services,
c) Desperate need of practical mechanism for the implementation of sustainable livelihood framework.

On the basis of above mentioned broad contexts, narratives highlighted the following:

- 'Culture of fear' associated with leprosy is a product of theological ideology that leads to cultivation of stigmatized perception and discriminatory practices against affected people.
- Stigma attached with the disease is the prime cause of discrimination practiced against them that leads to make them completely dependable on charity.
- 'Socially exclusive community' of leprosy sufferers is a result of government intervention of creating 'Space for House' from outside the community that leads to increase in gap between the Leprosy sufferers and mainstream society.
- After the elimination of leprosy from public health concern, policy makers have less attention towards the sustainable welfare of affected people that leads to promoting diabolic situations against leprosy sufferers in accessing socio-economic resources from the community.
- Due to social stigma attached with leprosy sufferers they are forcefully restricted to get married in their own community, called as 'Leprosy endogamous society'.
- There is a lack of proper sustainable government intervention in terms of implementing livelihood mechanism for the leprosy sufferers that propagate them for begging and rack picking for their survival.
- Context of discrimination in economic sector practiced against leprosy sufferers, changes from unorganized to organized way of pattern with the help of manipulation of acts.
- Government Implementation of 'Space for House' policy created leprosy colonies for the leprosy sufferers but leads to ostracized from the mainstream society.
- Depression experienced by leprosy sufferers leads to worsening their situation in terms of lived experiences in sustainable environment.

IX. INTERVENING CHALLENGES FOR SOCIAL WORK PROFESSIONALS

The narratives included in this research captured the real life experiences of leprosy sufferers in their recent past and also capture the popular tales and stories on leprosy and its association with discrimination. This narration worked as catharsis for the leprosy sufferers reflecting on the dark experiences they had. It seems as narrations provided them an instinct power to express and share their life situations which they had faced in their life till date and also helpful in develop the courage to tell their own agony.

Thus the popular common sense repertoire on leprosy and the narrations of the same could work as catharsis for the leprosy sufferers who themselves have experienced different diabolic situations in their life because of their disease but were reluctant to share those experiences.

Thus, the social work professionals like other human service professionals committed to the cause of public health need to get a right based approach on understanding leprosy and issues associated with it. There is a requirement of experienced, proper trained and positive mindset professionals across the nation to develop strategies based on action oriented approach for addressing the sensitive issues associated with the leprosy sufferers. For a positive social change, there is a need of scientific approach based on tested methods that are built on robust data for a better world in social work profession in achieving a better and sustainable outcome for the leprosy sufferers that makes a profound difference in their life.

The issue of leprosy requires a theoretical as well as practical concern with a high level of cultural sensitivity and intellectual acumen in the professionals to locate and eliminate the stigmatized attitude towards this disease, the institutionalized discrimination, organized ostracism, desperation and detachment with which affected people are unwillingly forced to separate themselves from society. In order to improve the aging condition of people suffering from leprosy, one of the most important steps is to provide them economic sustainability that leads to make them self- dependent and decision maker in solving their own problems. In this regard, it is a big challenge for social work professionals to get ready and acceptance from the policy makers to intervene in policy designing for the leprosy sufferers that provide financial sustainability to them.

Secondly, to eradicate the stigmatized perception towards leprosy, there is a need of awareness generation with proper sensitization at grass root level. In this regard theoretical lens of popular common sense repertoire could provide a window for the affected people to initiate discussion and share their views, pain and experiences with other community members. In this contemporary scenario, world is called as 'techno-materialistic world' which means that this era is more associated with technology and materialistic things. Thus, social work professionals can use social media like to expand and spread out the awareness among common people by using narrations of the affected people with their concern. This participatory approach on mapping and measuring the leprosy and its consequences because of practicing discriminatory practices with the affected people, could act as trigger to stop the discriminatory practices against sufferers. The forgoing discussion provided an idea on how the reintroduced understanding on leprosy could be helpful in working on this highly sensitive matter but a vital component of public health.

X. CONCLUSION

The whole study based on 'The Discriminatory Practices against Leprosy Sufferer and Gramscian Notion: Intervening Challenges for Social Work Professionals' concluded on the two broad dimensions; firstly, Due to isolation, leprosy sufferers experienced 'social death'. In order to overcome this problem, first and foremost important rehabilitative step is to provide social support to the patients and their family members need to properly counsel about the disease. In Gramscian notion of 'popular common sense repertoire', it is merely understood that ontologically, stigma against leprosy is rooted from traditional practices that create a 'culture of discrimination' against leprosy sufferers. This culture can be encountered only through generating proper awareness about the disease based on the empirical facts and logical discussions that gives an insight to the people to rethink and reinvigorate themselves about their practices and mindset.

Second dimension discussed about the sustainability of the leprosy sufferers in contemporary scenario. The provision of sustainability can be taken only after proper understanding towards the epistemological perspective of the leprosy. Epistemologically, leprosy is connected with my connotative definitions like 'bad blood', 'curse of God' and 'results of bad deeds'. This stigmatized perception towards the disease is one of the major causes of propagation of discrimination against the disease. In social work perspective, Popular Common Sense repertoire provide a platform based on practical implications that assess and evaluate the practice of stigma against leprosy sufferers and encountered with positive discrimination that provide an opportunity for the leprosy sufferers to grab the equal and accountable access of resources and power with transparency to eliminate the reproduction of unsustainable environment.

To develop a sustainable environment for the leprosy sufferers, there is a need of absolute elimination of stigma and discrimination from insight of the common people and by providing them job opportunities in a descent environment or by teaching those livelihood skills that provide earning for their living like fishing, farming, pot making etc. In light of positive perspective that 'this world is based on social relationship and all human beings are social animal', every person have the social responsibility to take care and provide support to the vulnerable people like leprosy sufferers.

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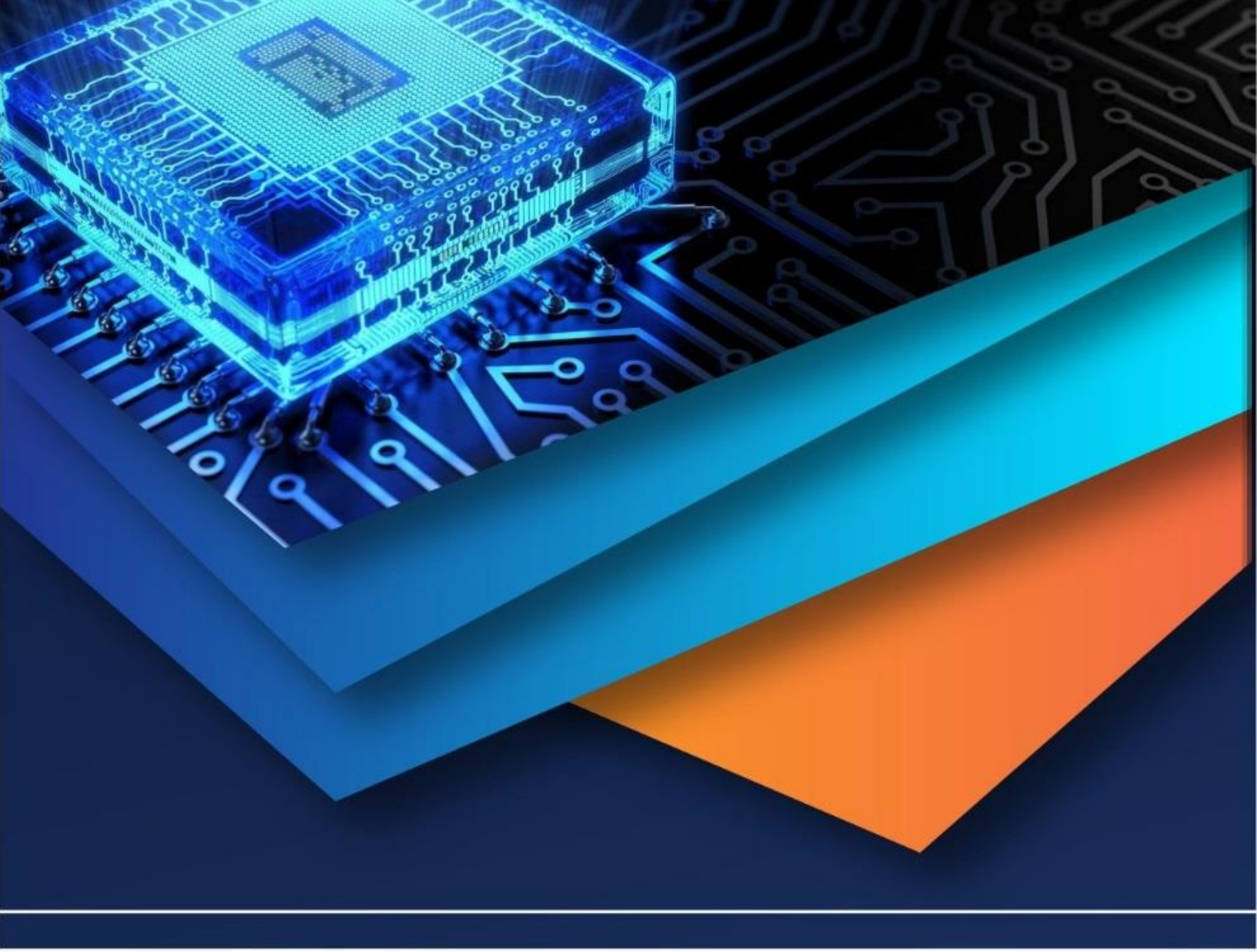

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