

Perspectives in Social Work

College of Social Work (Autonomous),
Nirmala Niketan
Mumbai

VISION AND MISSION

- Contribute to building a new social order based on human dignity and social justice.
- Work with a preferential option for the vulnerable and exploited, both locally and globally.
- Build cadre of young, competent professionals having a global perspective and a strong value base of compassion, personal integrity, moderation, tolerance and self-respect.

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EDITORIAL

This issue of *Perspectives in Social Work* brings together six insightful articles that engage with critical questions of ethics, education, health, disability, marginalization, identity, and social justice in contemporary India. The contributions collectively foreground the lived realities of marginalized communities and vulnerable populations while emphasizing the importance of inclusive, rights-based, and socially responsive interventions. Drawing upon qualitative, mixed-method, and field-based research approaches, the articles contribute significantly to social work scholarship and practice by centering voices that are often unheard within mainstream discourse.

The first article by Dr. Pandurang Vitthal Barkale examines the evolving role of campus journalists in higher education institutions. The article positions campus journalists as ethical storytellers, guardians of truth, and catalysts for positive social transformation. In an era increasingly marked by misinformation and disinformation, the paper highlights the responsibility of student journalists to uphold integrity, fairness, and transparency while fostering critical thinking and democratic engagement among students. It further explores emerging trends in storytelling and ethical journalism practices that can equip campus journalists to address contemporary challenges within university spaces and beyond.

The second article by Ayana Madhavan explores the role of education in enabling social mobility among Narikkuravar youth in Karamadai, Coimbatore. Focusing on a community that continues to experience deep-rooted marginalization despite its recent recognition as a Scheduled Tribe, the study critically examines how young people perceive education as a pathway to empowerment and social advancement. The findings reveal that although education is highly valued, structural inequalities, caste-based stigma, poverty, and cultural alienation continue to impede meaningful mobility. The article emphasizes the need for

culturally responsive educational frameworks, vocational opportunities, and collaborative support from social workers and civil society organizations to ensure equitable access and transformative outcomes.

The third article by Dr. Roshni Alphanso focuses on the health and nutritional challenges faced by Warli women in the Palghar district of Maharashtra. Using a convergent mixed-method design, the study highlights the complex interplay between poverty, tribal identity, cultural beliefs, and maternal health practices. The research reveals how harmful traditional practices and nutritional deficiencies adversely affect women during prenatal and postnatal stages. The article proposes several community-based interventions, including nutrition education, food security initiatives such as grain banks, and food-for-work programmes, while emphasizing the importance of stakeholder collaboration in addressing health inequities and advancing the goal of zero hunger among tribal communities.

The fourth article by Balaka Chattaraj critically examines the historical and ongoing marginalization of Adivasi tea plantation labourers in Assam. The paper traces the exploitative conditions under which Adivasi communities were forcefully migrated during the colonial period and highlights the persistence of poor living conditions, underpayment, identity exclusion, and health vulnerabilities even after legislative reforms. Based on primary data collected through in-depth interviews, the study sheds light on the structural inequalities and social neglect experienced by plantation workers. The article calls attention to the urgent need for policy reforms and social protection measures that uphold the dignity, health, and rights of tea plantation labourers.

The fifth article by Sharvari Pawar discusses Chronic Kidney Disease (CKD) as a growing public health concern in India and highlights the critical role of medical social work in supporting patients and caregivers. Using a mixed-method research design situated within the socio-ecological model of health, the study

explores the multidimensional challenges associated with chronic illness management. The findings reveal the emotional, financial, and psychosocial burdens experienced not only by patients undergoing dialysis but also by caregivers, who often remain invisible within healthcare systems. The article advocates for stronger psychosocial support systems, streamlined welfare and funding mechanisms, and comprehensive interventions that recognize caregivers as integral stakeholders in patient care.

The sixth article by Dr. Lidwin Dias and Dr. Kalyani Talvelkar addresses disability as both a human rights and development concern, emphasizing how social and environmental barriers restrict the equal participation of persons with disabilities (PwDs). Drawing on a survey conducted with support from the Rashtriya Uchchatar Shiksha Abhiyan (RUSA), the study examined the health, educational, livelihood, and psychosocial support needs of 300 persons with disabilities across 13 villages in Dholka Taluka. The findings reveal significant challenges related to access to healthcare, rehabilitation services, assistive devices, and livelihood opportunities, often compounded by financial constraints, lack of awareness, and delayed diagnosis of disabilities. The study further highlights the socio-demographic profile of respondents, many of whom belonged to marginalized communities and lived in joint family settings. By identifying critical gaps in service delivery and inclusion, the article advocates for strengthened disability-responsive policies, accessible healthcare and education systems, enhanced livelihood opportunities, and community-based awareness initiatives to promote empowerment, dignity, and social inclusion for persons with disabilities in rural areas.

Collectively, the articles in this issue reflect the enduring commitment of social work scholarship to engage with questions of equity, dignity, participation, and social transformation. They illuminate how systemic inequalities intersect with education, health, labour, media, and identity, while also offering grounded recommendations for practice, policy, and research. The issue

reinforces the importance of ethical engagement, participatory approaches, and interdisciplinary collaboration in addressing complex social realities and advancing inclusive development.

We hope this edition offers valuable insights to researchers, practitioners, educators, students, and policymakers engaged in the pursuit of social justice and human well-being. The reflections and findings presented in these articles aim to strengthen critical understanding, informed practice, and transformative interventions across diverse social contexts.

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**THE VANGUARDS OF VERACITY: CAPACITATING
CAMPUS JOURNALISTS FOR RESHAPING THE
SPHERE OF HIGHER EDUCATION.**

Dr. Pandurang Vitthal Barkale¹

Abstract

Campus journalists stand at a unique and powerful intersection: at the forefront of emerging trends within their university communities, while also serving as crucial guardians of truth and integrity. Their role transcends mere reporting; they are genuine catalysts for positive change. Through ethical storytelling, campus journalists can address the critical issues, hold power accountable, and foster an informed and engaged student body. This involves the commitment to accuracy, fairness, and transparency, ensuring that diverse voices are heard and that narratives are constructed with a deep sense of responsibility. As universities often incubate ground-breaking research, innovative ideas, and evolving social dynamics, campus journalists are uniquely positioned to identify and report on these emerging trends, translating complex information into accessible and engaging stories for their peers. By adhering to the highest ethical standards, campus journalists not only build trust within their immediate community but also cultivate essential skills that prepare them to shape the future of media. They are the frontline responders to misinformation and disinformation within their campus spheres, actively promoting a culture of critical thinking and well-reasoned discourse. In essence, campus journalists are not just recorders of history in the making; they are active participants in shaping it, empowering their communities with truth and integrity in an ever-evolving world.

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This paper gives a clarion call to capacitate the Campus Journalists to go on crusading for truth with integrity. The paper would also discuss various newer trends of storytelling used by journalists, espousing the path of ethics.

Keywords: Ethics, Integrity, truth, Journalism, campus, storytelling, Media Literacy, reforms, values, education, gender, equity, transparency, pluralism, crisis, accountability, AI

Introduction

Campus journalism, often seen as the training ground for future media professionals, has a much larger task to perform than merely reporting on university events. Student journalists, curious and burgeoning with a sense of responsibility, act as catalysts, upholding truth and integrity through the powerful lens of ethical storytelling. Student media often serve as the primary watchdog over institutional administration and the teaching community, investigating the decisions, questioning policies, and ensuring transparency and accountability. Campus Journalism serves as training for students interested in journalism, equipping them with critical thinking, research writing, teamwork, punctuality, creativity, presence of mind, and professionalism. Student journalists get to develop the interpersonal skills, communicative and interview skills, and leadership qualities, preparing themselves for more serious roles in the field. Their editing, proofreading, designing, and reporting skills are also honed during the exercise. Publication in Campus Journalism helps students understand, practice, and apply the ethics of publication. This journalism spreads awareness regarding the institutional policies, social concerns, triggering collective action against issues like deteriorating mental health, gender inequality, and environmental degradation. The publication allows students, faculty, and staff to exchange information, ideas, and opinions on issues of importance to students and the institution as a whole. The publication emphasizes academic, social, and cultural topics by allowing students to voice their opinions and spark conversation and awareness about current affairs and campus happenings.

The academic campus is a microcosm of society that houses individuals from class, caste, sex, race... Campus journalists are the bridge between the faculty, staff, administration, and the students; their core responsibility is to collect, verify, report, proofread, and publish the news for its accuracy related to the campus policies, academic changes and growth, along with the learning advancement, making sure that students, teachers, parents and alumni are well informed about what is happening within the institution. The campus report becomes documentation and accounts for happenings and events, recording the challenges and the achievements, including important updates about new programs, scholarships, examination schedules, or student help programs. This provides transparency and open communication on the campus, giving no space to misinformation and maintaining the smooth run for the academic and social discussion.

The goal of this study is to understand campus journalism as a catalyst for social change and to examine the role of student media in terms of their efforts at youth advocacy within the higher-education setting. By studying campus media's functional role and its active engagement in the areas of power, representation, and participation, the study will look into three questions as the primary driving force behind this research, and addressing these questions will show the important and expanding role campus journalism plays as a vital tool in negotiating the modern socio-political landscape.

1. How is campus journalism creating social consciousness and functioning as an advocacy medium for students?
2. How does campus journalism create a democratic environment and promote democratic participation inside and outside of the university environment?
3. How has the emergence of digital media changed the way campus journalism operates and provides a means of advocacy for students?

Conceptual Background of Campus Journalism

Campus becomes a laboratory for social interaction where individuals from diverse backgrounds come together, interact, and navigate the same complex challenges seen in the wider world. It is a place where learners can experiment and learn more about different regions, languages, ideologies, and socio-economic backgrounds. Institutions, rather than being passive educational spaces, have become active domains for protests, political change, and movements demanding transformation. Dorm rooms of the academic institutions are the public and private liminal zone where political and social interaction of thoughts allows honest conversation with continuous development of ideas with limited control of the institution, and therefore, they are called the launchpad for revolutions and movements. Significant examples of such sort are Student Movement (U.S.) (1960), The Velvet Revolution of Czechoslovakia (1989), The Tiananmen Square Protests, a massive student-led demonstration of Beijing in 1989 for free press, free speech, and democracy, The White Rose movement (1942-1943), a non-violent student movement in Nazi Germany led by siblings Hans and Sophie Scholl, with students and a professor.

Campus journalism, as a vehicle for providing student voice, is deeply rooted in an ethical framework that becomes the base for the practice of journalism. As reporters have an obligation to report accurately, fairly, and with respect for confidentiality, this obligation becomes of additional importance when considering the proximity of members of the campus community. The immediacy and personal nature of information reported through campus press can create added tension for student journalists as they must balance the public's right to know with the individual's right to privacy when reporting on sensitive issues, such as sexual harassment, mental health, and institutional conflicts. Thus, ethical campus journalism is also about developing empathy, accountability, and reflexivity in the act of reporting, not just about avoiding reporting false information. This ethical dimension of campus journalism enhances the practice of journalism in a way

that creates a culture of trust and credibility within the academic community; it positions campus journalism as an active rather than reactive practice that operates in a manner that is intentional and responsible.

Beyond its primary communicative function, campus journalism serves as a knowledge-producing practice through recording lived experiences, emerging issues of concern, and evolving cultural narratives within higher education spaces. This provides a space in which campus journalism responds to the need for greater analysis of the impact of emerging forms of communication through reflective and proactive practices. This means that campus journalism is both a reflective practice and a fundamental influence on accountability, transparency, and participatory governance within educational institutions.

Campus Journalists are the new age journalists who are guided by the commitment to truth and righteousness, researchers compelled by zeal and dedication to uncover the truth and challenge the moral stagnation of the time period. Their commitment to ethics and professionalism becomes the driving force and compass of the institution or university, and by practicing professional journalism, they enhance and encourage transparency, protecting and safeguarding the rights of people, while also changing the old norms by encouraging new exchange of ideas and perspectives. Students who study political theory and historical injustice imbibe critical understanding and political consciousness. Campus journalists are the crucial link between the faculty, staff, administration, and the students. Their core responsibility is to collect, verify, report, proof check, and publish the news for its accuracy related to the campus policies, academic changes, and growth, along with the learning advancement, making sure that students, teachers, parents, and alumni are well informed about what is happening within the institution.

The campus report chronicles the happenings and events, recording the challenges and the achievements, including

important updates about new programs, scholarships, examination schedules, or student help programs. This provides transparency and open communication on the campus, giving no space to misinformation and maintaining the smooth run for the academic and social discussion. In addition, social media, online campaigns, and digital storytelling allow young people to have immediate access and an expanded platform from which to promote their agendas and activities. Therefore, youth operate on the leading edge of societal, political, and cultural changes, including anti-colonialism, civil rights activism, demands for democratic reforms, feminist activism, and the fight against climate change. Campus Journalism can be seen as a learning platform and a catalyst for change, community building, responsibility, and social awareness, as well as coverage of sports, literature, creative arts, science, and cultural festivals, all within the educational framework.

Campus journalism provides students with both an outlet for their voices and an arena for exercising autonomy; however, what it provides does have a meaningful foundation of ethics to frame how this type of journalism will be carried out. As students pursue reporting, there is a heightened sense of accountability to do so truthfully, with accuracy, and with confidentiality by those who work in the tight-knit world of schools and/or universities because those individuals (the students) have been personally affected by something reported about them or someone they know. Campus journalists must consistently navigate the balancing act between the public's right to know and how to protect and preserve the dignity of those written about, particularly when dealing with sensitive issues of harassment, mental health. Therefore, ethical campus journalism is about more than preventing errors or misinformation; it is also about developing empathy, accountability, and reflexivity in telling someone's story through the act of reporting. The ethical lens of campus journalism will enrich campus journalism's potential in being a practice that not only responds to circumstances but is also responsible for creating a climate of trust and credibility in the greater institution of higher education.

In addition to serving a direct communication purpose, the reporting done by campus journalists assists in generating knowledge by documenting events of personal insight to the individual, events of concern being reported to the public, events that are impacting the community, and events that are changing societal stories entirely within the higher education community — an area previously not thoroughly examined in scholarly research. Therefore, campus journalism will be viewed not only as a mirror to reflect upon these historical examples but also as an integral contributor towards building accountability, transparency, and/or collaborative governance in colleges/universities.

Literature Review

“Campuses offer unique arenas that can act as incubators of civil society in which young people participate in student unions, groups, and societies and learn skills vital to citizenship, including democratic governance, independent organization, debating, and dialogue” (Milton and Barakat, 412).

Campuses may serve to be incubators of political ideology, hotbeds of cultural revolution, and fields of social change. The political ideology prevalent in the country includes nationalism, liberalism, resistance, and authoritarianism, which becomes a matter of campus discussion, protests, and student or university unions. Various ideologies keep oscillating inside the University campus. Campuses become a training ground for students aspiring for active politics in the world outside. In modern society, university campuses may function as accelerators and testing grounds for ideological and cultural change. Campus Journalists act as watchdogs, observing and tracking institutional and university policies, administrative decisions, and transparency by reporting on and investigating misconduct, protecting students' rights, and thus promoting civic responsibility among people.

Schools and colleges' newspapers, such as The Harvard Crimson, The Daily Pennsylvanian (University of Pennsylvania), The Yale Literary Magazine, echo the importance of students' publications

serving as an essential aspect of university or institution discussions. Online campus media, i.e., blogs, social media pages, digital sites, provide real-time coverage on achievements, academic changes, social events or issues, sometimes with the opportunity for the students to debut talk shows, conduct interviews, or express the critical and creative facets of news and current happenings through essays, poetry, and investigative features.

In research on campus journalism, two significant themes are explored: journalism education and media production as tools of institutional communication at universities. Though many studies on campus journalism focus on the development of journalism and related skills, which include ethical training and administrative operations of student-crafted media, few studies provide a comprehensive examination of the implications of the social and political dynamics of campus journalism. Some studies have explored the presence of student voices; however, the vast majority do not provide a rigorous examination of campus journalism as a stage for resistance, critique, or constructive dialogue. Additionally, there is a limited study of how the increasing presence of digital media has changed the way campus journalism reaches its audience, how quickly it reaches its audience, or the effect of that audience on campus journalism. As a result, the literature does not fully illustrate campus journalism as more than a pedagogical opportunity, but rather it exists in a continuously changing manner as a site for youth-based participation and advocacy, as well as a site for democracy. The current article seeks to address this gap by reconceptualizing campus journalism as an agent of social change through empowering students.

The literature increasingly states that campus journalism provides a space for students' expression and a space for youth to voice their social concerns around identity, inequality and institutional practices, enables participation in dialogue and fosters critical thinking. Interestingly, much of this existing literature is

descriptive in nature and does not fully examine how student media actively change the discourse, study or challenge the dominant power structures and system within and beyond the university. Recent scholarship and literature have paid significant attention to the role of digital media in campus journalism, specifically the shift to online journalism, social media engagement and live reporting. The change has broadened the reach and immediacy of student journalism, blurring the lines between reporting, activism, and public engagement. However, there has been a new lens of critical analysis on the impact of digital environment that affect credibility, authority, and the political.

Research Gap

The existing literature on campus journalism focuses primarily on the application of campus journalism as a training ground for media professionals and/or as an approach for students to express themselves. It performs the role of communication between the institution and the broader public. Yet, this area has received limited scholarly attention to the interdisciplinary importance of campus journalism, specifically in its connection to social work, youth advocacy, and the development of students' critical consciousness. Most studies of campus journalism are predominantly descriptive in nature, reporting on the functions and challenges of campus journalism; however, there is no critical examination of how campus journalism can be seen as a part of creating social change and increasing democratic participation and awareness of campus life through student media. Additionally, there is also a lack of research studying how the emergence of electronic media has completely changed campus journalism from a platform for disseminating information and student-created content to a mechanism for real-time communication and activism. Therefore, this gap calls for a more substantive examination of campus journalism as a communicative practice and as an agent for social transformation and student empowerment.

Research Methodology

The article utilizes a qualitative, interpretative methodology based on secondary data sources to examine campus journalism as it pertains to higher education. This study uses qualitative interpretive methods and analyses of multiple types of documentation, such as academic journal articles, books, pieces of public policy, and reliable online and web sources. The thematic review of literature identifies four key themes: Student Voice, Advocacy, Democratic Participation, and the Changing Face of Digital Media (i.e., the changing role of digital media). Sources studied in the analysis were chosen for their relevance to campus journalism, timeliness, and their contributions to conversations around youth engagement and media use. The methodology used allows for a critical understanding of existing literature and looks at campus journalism as a source for active social change.

A close reading of source material, drawn from media studies, education, and socio-political discourse, informs the study. The material has been purposefully chosen and studied in order to look at the students' media understanding, youth involvement, and the impact of digital technology. Furthermore, the study has been drawn from current sources in order to reflect the shifting environment of campus journalism within a more-connected society.

This research relies heavily on secondary sources, which not only capture the real experience of student journalists but also allow for a more systematic critical synthesis of existing knowledge and the development of a broader understanding of campus journalism in general. The methodology is focused on interpretation instead of measurement, in accordance with the objective to examine campus journalism not only as a communicative vehicle, but as a critically significant site where power, participation, and representation are constantly being negotiated.

Campus Journalism as a Site of Democratic Engagement and Social Transformation

Young people in many societies may be looked down upon for being inexperienced and, at times, disregarded as powerless, spoiled, or lazy. They are expected to conform to and comply with the authorities and prevalent rules without having their own opinion. However, there are ample examples of students responding to the oppression and injustices in society. Many student-led protests have changed the world. Student protests such as The Fisk University protests of 1925, The Greensboro sit-in of 1960, The Kent State University shooting of 1970, The Tlatelolco massacre of 1968, The Soweto Uprising of 1976, March for Our Lives-2018, and The Global Climate Strikes-2019 had taken the states by storm. Campuses are the combat zones in the literal and metaphorical sense. Wars, armed conflicts, and battles on the school and university grounds across different generations have made a big change, and educational spaces have been repurposed as defensive positions during times of conflict. The American Revolutionary War (Battle of Princeton in 1777, campus of what is now Princeton University) exemplifies how universities and institutions can be turned into military conflict. The American Civil War (University of Mississippi)- a military encampment for Confederate troops, served as a staging and training location for the military during that conflict on behalf of the Confederate Army. These examples indicate that campuses have experienced not simply "exposure" to violence but were incorporated into social and political conflict. During the Siege of Lucknow (1857) and the Indian Rebellion of 1857, La Martinière College in Lucknow, during colonial India became a fortified area, demonstrating how educational institutions were literally transformed into battlegrounds in resistance to imperial control. Authoritarian regimes obliterate campuses as locations for acts of resistance and, in addition, convert them into means for enforcing conformity to the regime's ideology through regulatory measures, including curriculum restrictions, control of faculty appointments, limits on student speech, and criminalization of student demonstrations.

Campus Journalism as a Democratic and Ethical Institution

The university is a sanctuary for home and unhomeliness. Colleges and universities are a second home for students as they get the opportunity to grow intellectually, socially, and personally. Many students believe college provides them with a refuge from societal and personal norms of behavior, family expectations, and politics. Students create a new "home", redefine their identity, and grab the opportunity to develop their curiosity and pursuit of knowledge. Therefore, colleges and universities are safe havens for critical inquiry and exploring oneself. Campus journalism is the student-driven publication that challenges and institutionalizes societal equality, justice, and human dignity, ensuring that these changes are a permanent part of the societal framework, influencing future generations for change and shaping public awareness and transformation by independently working on ethical storytelling. Their commitment to ethics and professionalism becomes the driving force and compass of the institution or university, and by practicing professional journalism, they enhance and encourage transparency, protecting and safeguarding the rights of people, while also changing the old norms by encouraging new exchange of ideas and perspectives.

Media, as the fourth pillar of democracy, serves to be a watchdog, a guardian of the public interest, and a conduit between government and the governed. Campus Journalists, similarly, observe and track the institution and university policies, administrative decisions, and transparency by reporting and investigating the misconduct, protecting the rights of the students, thus promoting civic responsibility among people. For responsible and ethical journalism, investigative reporting is essential in institutions and universities, to uncover the important issues that would otherwise be buried. Investigative Journalism would foster transparency, trust, and accountability between the students and the institution. It explores the root cause of the issue by understanding the historical context and future possibilities. Rigorous investigation helps the journalist to observe the college campus and culture to understand and address the problem, report

truthfully and responsibly with careful sourcing and accuracy. For example, while reporting on the poor washroom facilities, investigative journalism would study the reason behind the poor condition of the washroom, considering various factors such as budget, improper planning, lack of maintenance ...The investigative report will also include the management of the college regarding the school complaints, maintenance, schedule, or plan update, along with the interaction and feedback of students and faculty. This comprehensive coverage of the report keeps transparency between the organization and readers, helping students understand the campus better, with informed opinions, preparing students for ethical journalism and informed decision-making.

To promote a culture of transparency and efficiency, where errors are promptly accepted and rectified, campus journalism helps as a trusted source for information, news, and knowledge, as it is based on factuality, encouraging accountability and openness between the journalists and the audience. Campus journalists adhere to ethical behavior and professionalism with the right method of report writing. They accept and review their mistakes rigorously by taking into consideration potential misinterpretation, which make the readers feel more connected to these reports, as it builds a culture of dialogue within the campus community, where readers are more likely to take initiatives for solving and fostering an environment by taking actions and collaborating for a social cause. This teaches the aspiring journalists to be accountable for their reports and actions, to value credibility, and to have the power to communicate honestly within the campus and outside.

Digital and Ethical Transformation of Campus Journalism

In the contemporary world, the emergence of digital technologies has reshaped the media landscape in India. The increasing engagement of the internet and social media has altered the consumption of news; it now provides instant access to information, promotes citizen journalism, and offers novel opportunities for activism and public engagement. Digital media

has connected India to a global audience while promoting a vibrant and interactive format for debate, discussion, and democratic participation. The advancement of media technology has significantly changed the way in which information is conceived, shared, and experienced.

Campus journalists educate and uphold the ethical guidelines by avoiding plagiarism, conflict of interest, and sensationalism while, laying the groundwork for integrity, accountability, and focusing on the principles of journalism, i.e., to inform, educate, strengthen, and give voice rather than misleading and misinformation. Avoiding plagiarism becomes the cornerstone of ethical writing as it depicts the quality, honesty, and credibility of the publication in educating campus journalists by appropriately teaching them proper citation, paraphrasing, and academic integrity. The notion of journalism that values authenticity and transparency teach the aspiring journalist to avoid situations where there could be conflicts of interest, for example, covering stories of close people, where the objectivity of journalism can be compromised. Campus Journalism helps to promote respect for privacy and confidentiality while balancing the public's right to know, by writing about topics or issues that involve students, faculty, staff, or administration people who belong to the same community. As an important form of protection, privacy and confidentiality maintain trust and integrity by respecting the privacy of people who live and belong to the same community. Especially, reporting on sensitive cases, for example, harassment, mental health, or punishment, must be done without revealing or damaging the name, approaching the report in a humanitarian way with implication of awareness, but also taking into consideration the public's right to know the fundamentals. Campus journalists should understand how to balance the tension between protecting individuals' privacy and serving the broader public interest through truth and transparency. The ethical problem is often about deciding what type of information is necessary for the audience to know and what is not, and where that lack of oversight breaches into intrusion.

By understanding and self-reflecting, student journalists can decode their own biases and minimize them in their reports. Self-reflection encourages professional learning and development through self-learning, learning from their own errors, and considering the impact and implications of their story and report on society. When reporters evaluate their stories and analyze their own perspectives, they become aware and sensitive about issues related to gender, caste, culture, and identity, giving voice to the underrepresented and marginalized people. Along with the ethics of Journalism, self-reflection in Campus Journalism is an effort to deliver truth with responsibility, following the ethics without prejudice and stereotype.

Implications for Social Work

Campus journalism holds significant relevance for social work, specifically related to the ability to provide an advocacy tool by creating and spreading awareness and engaging with youth involved in Higher Educational settings. Student-centered areas of media on campus can shed a light on important themes such as mental health concerns, gender inequality, discrimination, and institutional barriers, to effectively serve student populations by documenting and distributing issues significant to them thus, aligning with the main goals of Social Work - Social Justice, Amplifying Voices of Marginalized Populations and Creating Informed Dialogue.

The investigative aspect of Campus Journalism reinforces its similarities to Social Work through the use of research and investigation that examine the underlying causes of institutions' issues (i.e., inadequate infrastructure, insufficient resources, maladministration) in order to create transparent institutions that hold themselves accountable to the communities they serve. Social Workers utilize similar advocacy methods that provide solutions for addressing systemic inequalities within their communities while working towards changing policies for the betterment of those communities.

Campus Journalism makes the youth who are socially aware and critically minded, responsible towards society. By enrolling in journalistic activities, young students and scholars experience the application of critical thinking, ethical reasoning, communication and leadership skills. These skills are significantly important in every aspect of social work, where there is a need to analyze and understand complex issues that are largely affecting society. Ethical journalism has a sustained focus on values such as respect for privacy, unbiased reporting, and sensitivity to those who are vulnerable, which aligns with the core values found in social work practice.

In addition to being a traditional form of communication, Campus Journalism is a community-engaged and participatory medium; it allows for real-time and interactive exchange of information, facilitates dialogue about social issues, and brings together students who are mobilized around a common social cause. The participatory feature of Campus Journalism enhances the collective consciousness of students, leading them towards taking action regarding social issues, thus creating an informed, empowered, and socially conscious group of youth.

As a result, Campus Journalism can be understood as the extended version of the principles of social work in an academic environment and setting. Rather than functioning merely as a form of communication, with the support of advocacy, accountability and community engagement, Campus Journalism plays a vital role in producing socially conscious individuals and contributing to the development of a democratic society within post-secondary institutions.

Conclusion:

Campus journalists are not just observers but are active participants in the democratic discourse of the country. As aspiring professionals, campus journalists are indispensable catalysts for truth, integrity, and the discerning exploration of emerging trends. Through their commitment to ethical storytelling, they not only chronicle the present but also actively

shape the more informed and responsible future. Their unique position within academic communities allows them to scrutinize narratives with a critical lens, unearthing hidden truths and challenging misinformation that proliferates in an increasingly digital world. By adhering to principles of accuracy, fairness, and transparency, campus journalists build a foundation of trust, reinforcing the very integrity that is often eroded in the broader media landscape. Collaboration and ethical reporting make campus journalism a platform for students and readers where they contribute their individuality, creativity, and reader engagement to develop and foster public opinion. Students become more aware of decision-making, social responsibility, leadership, and ethical conduct. With the blend of investigation, effective collaboration, civic engagement with student-led research and observation, campus journalism can achieve its goal to inform, inspire, and add to the social and cultural changes on the campus and in society. With misinformation and ideology changing the educational landscape, campus journalism serves as a pillar of democratic practice within education. Its growth and continued development across many locations, such as the United States, UK, Canada, Philippines, Germany, and India, show us that Campus Journalism is becoming an integral part of youth participation aesthetically and intellectually, around the world.

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**A QUALITATIVE STUDY ON THE ROLE OF
EDUCATION IN THE SOCIAL MOBILITY OF
NARIKKURAVAR YOUTH IN KARAMADAI,
COIMBATORE**

Ayana M¹, Dr. Sr. S. Emelda Mary²

Abstract

This study explores the role of education in enabling social mobility among Narikkuravar youth in Karamadai, Coimbatore, a community recently recognized as a Scheduled Tribe but still facing deep-rooted marginalization. Using qualitative methods including interviews, key informant discussions and participant observation with 15 Narikkuravar youth in Karamadai, the study investigates how youth perceive education as a means of upliftment while navigating poverty, gender bias, cultural alienation and systemic exclusion. Findings reveal that although education is valued, it does not automatically lead to mobility due to persistent structural and cultural barriers. Theoretical insights into cultural capital, social stratification and human capability, highlight how institutional shortcomings and caste-based stigma undermine educational outcomes. The study concludes by recommending culturally responsive curricula, inclusive policy frameworks, vocational training and collaborative efforts from NGOs and social workers to ensure that education becomes a truly transformative force in the lives of Narikkuravar youth.

Keywords: Capability Approach, Cultural Capital, Narikkuravar Youth, Social Mobility, Tribal Education.

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Introduction

The Narikkuravar, a semi-nomadic community in Tamil Nadu, have historically been subjected to deep-rooted social exclusion and economic marginalization. With their traditional livelihoods disrupted by wildlife protection laws and urban development, education has emerged as a potential tool for upward mobility. (Vijayabaskar & Kalaiyaran, 2021) The Indian government's recent move to grant them Scheduled Tribe (ST) status aims to redress historical injustices by improving access to education and employment. However, despite policy interventions, Narikkuravar youth continue to face challenges including poverty, school dropout and systemic discrimination. According to the 2021 Annual Report of the Ministry of Tribal Affairs, only 6.6% of ST youth aged 18-23 in Tamil Nadu pursue higher education compared to a state average of over 20%, highlighting persistent disparities despite increased access. Situated in Karamadai, Coimbatore, a region marked by high literacy but persistent inequality, this study investigates how education affects the life trajectories, aspirations and identities of Narikkuravar youth. It aims to identify the barriers and enablers within educational systems and explore whether current frameworks are adequate in transforming access into real opportunities. By adopting a qualitative approach and grounding the analysis in established sociological theories, this study offers critical insights into the structural conditions that mediate the effectiveness of education as a tool for social transformation among one of India's most marginalized tribal communities. This study seeks to answer the central question: To what extent does access to formal education lead to meaningful social mobility among Narikkuravar youth in Karamadai, and what barriers persist in preventing the translation of educational access into opportunity.

Research Methodology

Research design

This study adopts a qualitative exploratory research design to examine how education influences the social mobility of Narikkuravar youth in Karamadai, Coimbatore, Tamil Nadu. This

design enables an exploration of the participants lived experiences and contextual challenges, which are often inadequately captured by quantitative methods.

Study Area

The research is localized in Karamadai, a semi-urban area in Coimbatore district, Tamil Nadu, which presents a striking contrast between regional literacy and development and the marginalization of the Narikkuravar community residing there. Although Coimbatore district has a general literacy rate of 84%, informal estimates by the NGO (Helping Hands) suggest that the literacy rate among the Narikkuravar in Karamadai is closer to 40%, reflecting deep-rooted educational exclusion within an otherwise developed region.

Sampling and Participants

A purposive sampling technique was employed to select 15 Narikkuravar youth aged between 15 and 30 years. The sample comprised:

- i. School and college students
- ii. School dropouts
- iii. Educated but unemployed youth
- iv. Employed individuals with educational qualifications

This diversity allowed for the inclusion of varied educational trajectories and social mobility experiences.

The following table presents the profile of the 15 participants, capturing differences in age, gender, education level and current socio-economic status.

	Age	Gender	Education Level	Current Status
Gandhi	18	Male	Class 12 (ongoing)	Student
Senthamizh	20	Female	Class 8 (Drop out)	Household work
Karthik	25	Male	Diploma in Engineering	Unemployed
Rithvik	22	Male	B.A. Degree	Preparing for govt exams
Lakshmi	17	Female	Class 11 (ongoing)	Student
Mahadev	28	Male	Class 10	Traditional vendor
Mira	23	Female	Class 5 (Drop out)	Daily wage labourer
Anya	19	Male	ITI (Electrician)	Apprentice technician
Rudra	16	Male	Class 9	Student
Dinesh	21	Male	Class 12 (pass)	Shop assistant
Anvitha	24	Female	B. Com (Dropout)	Helping in family business
Sanjay	26	Male	Class 8	Beadwork vendor
Indira	27	Female	No formal education	Selling fox tails
Ramesh	20	Male	Polytechnic Diploma	Looking for private jobs
Deva	15	Male	Class 10 (ongoing)	Student

Data Collection Methods

- In-depth semi-structured interviews with Narikkuravar youth were conducted to explore their educational aspirations, institutional experiences, perceptions of discrimination, and views on social mobility.
- Key informant interviews with parents, teachers, and local social workers provided broader community and institutional perspectives.
- Participant observation and informal discussions offered contextual insights into cultural dynamics, daily routines, and patterns of educational access.

Each in-depth interview lasted between 30 to 45 minutes and was conducted in Tamil, the native language of both the participants and the researcher. Informal conversations and participant observations extended over a three-month field period. All interviews were manually transcribed and translated into English where necessary.

Data Analysis

Data were analysed using thematic coding through manual methods. Thematic patterns were identified and interpreted within the framework of Bourdieu's cultural capital, Weber's social stratification and Sen's capability approach. These frameworks helped contextualize the barriers and enablers of social mobility through education.

Ethical Considerations

Special attention was given to the vulnerable status of tribal communities:

- Informed consent was obtained with clarity about the study's purpose and withdrawal rights.
- Confidentiality and anonymity were strictly maintained by de-identifying participants and using pseudonyms.
- Cultural sensitivity was ensured through Respect for local customs, Non-coercive participation, Community consultations where needed.
- The research aligned with National ethical guidelines for working with vulnerable and Indigenous populations.

Statement of the Problem

Despite gaining Scheduled Tribe (ST) status and access to welfare schemes, the Narikkuravar community continues to face deep-rooted marginalization that restricts their access to quality education, healthcare and employment. The community now struggles with limited representation and “unfair competition” within the ST quota system, where more established groups dominate available opportunities. Narikkuravar youth face compounded barriers such as poverty, inadequate infrastructure and systemic discrimination in schools. Cultural irrelevance of curriculum, lack of vocational training and language barriers further alienate them from education. These challenges highlight structural gaps in policy implementation and call for a culturally sensitive, inclusive educational approach.

Objectives of the Study

- To explore how formal education contributes to the social and economic mobility of Narikkuravar youth in Karamadai.
- To identify structural, cultural and institutional barriers that affect educational access, retention, and outcomes among the community.
- To document lived experiences and aspirations of Narikkuravar youth navigating mainstream education systems.

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- To analyse the effectiveness of ST status and government schemes in transforming educational participation into meaningful life outcomes.
 - To recommend culturally responsive educational strategies and policy interventions for sustainable tribal empowerment.

Limitations

This study is limited by its small, purposive sample size, which restricts generalizability. The findings reflect the experiences of Narikkuravar youth in Karamadai and may not represent other geographic or cultural contexts. Language barriers and social desirability bias during interviews may have influenced responses. Additionally, access to female participants was more limited due to cultural constraints.

Researcher Reflexivity

As an outsider to the Narikkuravar community, the researcher remained aware of positionality, potential biases and power dynamics throughout fieldwork. Efforts were made to build trust, practice cultural humility and allow participant's voices to guide the narrative. Reflexive journaling was used to track assumptions and ensure ethical, respectful engagement.

Data Saturation

Data saturation was reached when no new themes or significant insights emerged from subsequent interviews and observations. Although the sample size was limited to 15 participants, the diversity of the sample including school-going students, dropouts, unemployed graduates and employed youth, ensured a rich range of experiences. Thematic repetition across interviews indicated that the key issues related to educational access, cultural dissonance and institutional exclusion had been sufficiently captured to answer the research objectives. Saturation was also supported through triangulation with key informant interviews and participant observation.

Acknowledgement

The researcher gratefully acknowledges the Narikkuravar community of Karamadai for their openness and trust. Special thanks to local social workers, schoolteachers and NGO representatives who facilitated access and insights. This research would not have been possible without their support and collaboration.

Review of Literature

This section synthesizes academic and policy-based literature on education, tribal development and social mobility, establishing a contextual foundation for the present study.

Education is a key driver of tribal development in India, with the Constitution mandating special provisions for the upliftment of Scheduled Tribes (Sts). However, despite policy attention, glaring disparities persist. The literacy rate among STs was 58.96% in 2011 and increased to 72.1% by 2022, yet it remains below the national average. Dropout rates, particularly at the secondary level (24.9% in 2014-15), continue to be a major concern. A 2023 report by the Government of Tamil Nadu noted that dropout rates among ST girls in rural belts like Mettupalayam and Karamadai remain as high as 33% by Class 10, pointing to the compounded impact of gender, geography and community status.

To address these gaps, both central and state governments have introduced initiatives such as Ashram Schools, Eklavya Model Residential Schools, and financial aid programs including post-matric scholarships, fee waivers and free uniforms and textbooks. (Ministry of Tribal Affairs, 2020) Additionally, schemes supporting coaching for competitive exams and international study grants have been implemented to expand higher education access for tribal youth. Despite these efforts, structural challenges undermine outcomes. Geographical isolation, language barriers and irrelevant curricula diminish engagement and learning. Many tribal students speak indigenous languages at home, while instruction is delivered in Tamil or English, creating linguistic

dissonance. (Mohanty, 2009) Curricula often fail to incorporate tribal worldviews, contributing to alienation. Furthermore, infrastructural deficits such as inadequate classrooms, sanitation and teaching materials remain persistent, particularly in remote areas.

While enrolment has improved quantitatively, the qualitative experience of education, its inclusivity, relevance, and impact remains insufficiently addressed. These persistent gaps underscore the need for localized, culturally sensitive interventions that go beyond mere access to ensure meaningful participation and long-term social mobility for tribal youth.

Theoretical Lenses

To explore the relationship between education and social mobility among Narikkuravar youth, this study draws upon three key theoretical frameworks: Bourdieu's Cultural Capital, Weber's Social Stratification and Sen's Capability Approach.

Bourdieu's Cultural Capital Theory

Pierre Bourdieu argues that education systems often reproduce social inequality by privileging the cultural norms of the dominant class. Cultural capital exists in three forms: embodied (skills and dispositions), objectified (cultural goods) and institutionalized (qualifications). For the Narikkuravar, their traditional knowledge such as beadwork and hunting skills is undervalued in formal education, creating a disconnect between their cultural identity and the expectations of the school system. Even with institutional recognition like ST status, the absence of dominant cultural capital continues to hinder their educational and professional integration. (Bourdieu, 1986)

Weber's Theory of Social Stratification

Max Weber highlights that social mobility is shaped not just by economic class, but also by status (social prestige) and party (political power). For Narikkuravar youth, education may improve economic prospects, but entrenched caste stigma and

limited political representation continue to constrain their overall mobility. This framework explains why upward movement in one dimension (e.g., education) does not always lead to holistic social advancement. (Weber, 1978)

Sen's Capability Approach

Amartya Sen redefines development as the expansion of individual capabilities, the real freedom to lead a life one values. Education, in this view, is a means to an end, not the end itself. If Narikkuravar youth face discrimination, irrelevant curricula, or economic hardship, their ability to convert education into meaningful outcomes (like secure employment or dignity) remains limited. Sen's framework emphasizes the need to assess not just access to education, but also its transformative potential in lived contexts. (Sen, 1999)

Findings

This qualitative study highlights the complex and uneven relationship between education and social mobility for Narikkuravar youth in Karamadai. While education is widely viewed as a vehicle for advancement, its impact is shaped by intersecting socio-economic, cultural and institutional barriers.

The following key themes emerged from the data:

Theme 1: Educational Access and Aspirations

Narikkuravar youth view higher education as a crucial pathway to escaping poverty and attaining dignity. For many, education represents self-improvement and the potential for family upliftment. However, gender-based restrictions remain a significant barrier, with girls often facing greater limitations due to entrenched patriarchal norms. Encouragingly, some shifts in community attitudes are emerging in support of girl's education. Many youths expressed hope in education as a way to 'escape this life of struggle'. Gandhi (18), a Class 12 student, shared: 'I want to study and become a teacher. People still look at us differently, but with education, we can stand up'. Lakshmi (17), a Class 11 student, shared: "I want to complete college. Earlier, no girl from our street

went this far. My mother tells me I can do more.”

Theme 2: Barriers to Educational Continuity

A combination of persistent poverty, early marriage, lack of transportation, inadequate infrastructure and shortage of trained teachers continues to hinder educational continuity. Additional challenges include discrimination from teachers and peers, a culturally irrelevant curriculum, and the absence of vocational pathways, all of which contribute to student disengagement and dropout. Senthamizh (20), a school dropout, recounted: “My father said girls should not go to school after puberty. So, I stayed home, helping my mother with beadwork.”

Theme 3: Identity and Self-Perception

Education fosters self-awareness, confidence, and political consciousness among Narikkuravar youth. However, it also leads to cultural dissonance and internal conflict. Many participants reported feeling alienated, estranged from both mainstream society and their traditional community resulting in identity confusion and emotional isolation. Rithvik (22), a college graduate, noted: “I studied and got a degree. But in college, they laughed at my language, my clothes. Even now, I don't belong there or here.”

Theme 4: Employment Opportunities

Despite attaining educational qualifications, many Narikkuravar youth remain jobless or underemployed, often due to systemic discrimination and a lack of culturally inclusive workplaces. Some ultimately return to traditional or informal occupations after experiencing exclusion or discomfort in formal sectors. Karthik (25), who holds a diploma, explained: “They want us to study but won't give us jobs. I went to ten interviews and got rejected when I told them my caste.”

Theme 5: Perceived Social Mobility

While a few participants reported minor improvements in lifestyle and recognition within the community, the majority felt that

education alone has not significantly enhanced their socio-economic status. Structural inequalities, especially caste-based discrimination, continue to restrict meaningful upward mobility, even after the conferment of Scheduled Tribe (ST) status.

The findings affirm that education is a necessary but insufficient condition for social mobility among Narikkuravar youth. While aspirations are high, systemic poverty, discrimination and cultural alienation inhibit the conversion of education into tangible life outcomes. Moreover, formal schooling often fails to acknowledge or incorporate the community's cultural capital, weakening its transformative potential. Genuine upward mobility, therefore, demands holistic interventions beyond enrolment, addressing economic precarity, cultural inclusion, and institutional reform.

Discussion

The findings reveal that while education is widely viewed by Narikkuravar youth as a pathway to upward mobility, its impact is significantly constrained by structural and cultural barriers. This complexity is best understood through the theoretical frameworks of Bourdieu, Weber and Sen.

Bourdieu's Cultural Capital

Educational attainment among Narikkuravar youth often fails to yield social mobility because their embodied cultural capital such as tribal language, traditional skills, and lifestyle is not valued within mainstream institutions. Despite acquiring degrees (institutional capital), they face systemic exclusion due to their inability to conform to dominant cultural expectations. This mismatch reinforces marginalization, showing that schooling alone does not equate to social acceptance or advantage.

Weber's Social Stratification

Weber's multidimensional view explains how even educated Narikkuravar youth remain disadvantaged. Their economic class may improve, but their historically low status and negligible political power (as a small and underrepresented group) limit real mobility. Discrimination in schools and workplaces diminishes

their social standing, illustrating that education alone cannot dismantle caste-based hierarchies.

Sen's Capability Approach

Sen's framework emphasizes that access to education is not enough, it must translate into the freedom to lead a valued life. For Narikkuravar youth, persistent discrimination, irrelevance of curricula, and economic precarity often prevent them from converting education into meaningful outcomes such as secure employment, dignity, and social recognition. Their capabilities remain constrained, highlighting that systemic change is essential alongside educational access.

Role of Social Workers

Social workers play a crucial bridging role by promoting literacy, sensitizing schools, facilitating access to schemes, and advocating for culturally inclusive education. (Desai, 2012) Their engagement is vital for translating policy into practice and ensuring that education genuinely uplifts tribal youth.

The intersection of cultural capital deficits, social stratification and constrained capabilities illustrates why education, though essential, is insufficient on its own. For Narikkuravar youth, true social mobility demands a multi-pronged approach combining culturally responsive pedagogy, structural reforms, vocational pathways and anti-discrimination efforts across institutions.

Recommendations

1. Develop bilingual and culturally relevant curricula that integrate Narikkuravar language, culture, and traditional knowledge. This approach enhances student engagement, promotes cultural identity, and reduces alienation caused by mainstream content.
2. Improve school infrastructure and transport access in or near Narikkuravar settlements. Ensuring proximity and safety can significantly reduce dropout rates, especially for girls, and improve regular attendance.
3. Ensure effective implementation of existing government

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- schemes, including scholarships, free uniforms, smart classrooms, hostels, and science labs. Access to these entitlements removes financial burdens and encourages educational continuity among low-income tribal families.
4. Enact and enforce anti-discrimination legislation in educational institutions to eliminate caste-based practices and ensure inclusive learning environments. Legal protection builds student confidence, reduces stigma, and promotes equality in academic spaces.
 5. Introduce vocational training programs that combine traditional skills (e.g., beadwork, animal care) with modern employment pathways. This creates livelihood opportunities that are culturally sustainable and economically viable.
 6. Provide structured career counselling and placement services tailored to tribal students. Guided pathways can help students transition from education to employment more effectively, addressing underemployment.
 7. Expand access to skill development and internship grants to improve employability. Hands-on experience helps bridge the gap between academic learning and real-world job markets.
 8. Conduct regular teacher sensitization and training programs to address unconscious bias and foster respect for tribal identities. Empowered teachers create more inclusive and empathetic classroom environments.
 9. Reform curricula to include themes of social justice, equality, and inclusion, starting from the primary level. Embedding these values early helps challenge caste-based hierarchies and cultivates democratic citizenship.
 10. Establish confidential grievance redressal systems in schools to address caste-based harassment and ensure accountability. Safe reporting mechanisms empower students and reinforce institutional commitment to equity.
 11. Foster collaboration between NGOs and government bodies to deliver holistic services such as education, healthcare, and cultural programs. Multi-stakeholder
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involvement ensures comprehensive support and strengthens program implementation.

12. Support and strengthen the role of social workers in advocacy, community engagement, and bridging access to entitlements. Social workers play a key role in empowering marginalized families and navigating bureaucratic systems.

Conclusion

This study highlights the complex and layered relationship between education and social mobility among Narikkuravar youth in Karamadai, Coimbatore. While education is widely regarded by the community as a critical tool for breaking cycles of poverty and marginalization, its actual impact remains limited by persistent socio-economic, cultural and institutional barriers. Factors such as poverty, discrimination, curriculum irrelevance and cultural dislocation significantly hinder educational continuity and outcomes. Although the recent attainment of Scheduled Tribe (ST) status has opened doors to welfare schemes, the Narikkuravar still face “unfair competition” and systemic exclusion within both educational and employment domains. The application of Bourdieu's, Weber's, and Sen's theoretical frameworks reveals that formal access to education does not automatically lead to enhanced capabilities, higher status, or genuine inclusion. For education to function as a true catalyst of mobility, it must be inclusive, culturally sensitive and supported by strong institutional and community-based interventions. Therefore, a shift is needed from mere access to meaningful engagement through vocational training, legislative reform, teacher sensitization and grassroots collaboration. Only through such holistic measures can the promise of education be fully realized for Narikkuravar youth, enabling them to lead empowered and dignified lives within both their community and the broader society.

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**BELIEFS & PRACTICES DURING PREGNANCY AND
POST-PARTUM PERIOD AMONG WARLI WOMEN
IN MAHARASHTRA: A CONVERGENT DESIGN**

Dr. Roshni Alphanso¹

Abstract

The central phenomenon explored in this article is the key issues of Adivasi (Warli) women's health of Palghar District in Maharashtra by using convergent mixed methods of enquiry. It precisely ascertained the socio-cultural context of poor nutrition regarding the prenatal and postnatal care patterns, which adversely affect women's health. Using a pragmatic paradigm, the researcher spent six months in the village and interviewed 305 Warli women. Ethical protocols were maintained during the entire research process. The field evidence indicates that Warli women suffer a triple burden: Being a tribal woman, Poverty versus cultural beliefs, especially during reproductive stage. As per tradition, a woman receives her first meal three days after her delivery. Rudimentary practices continue even today. A common belief supporting these practices is that breaking the rule will lead to a disaster. To enhance the nutritional status of Warli women, it is proposed that women should be given adequate food including green veggies, soups, fruits and milk to regain their health. Food for work programmes need to be introduced in villages where there is absolute poverty. Establishing Grain banks will ensure access to food during lean periods so that people do not die of hunger. Warli diet is carbohydrate focussed and protein deficient. Demonstrating nutritive recipes focussing on diet diversity is imperative in the Warli hamlets. Networking with multiple stakeholders is the key to achieve the goal of zero hunger and address the inequities among women in the health sector.

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Key words: Beliefs, Cultural Practices, Pregnancy, Postpartum and Tribal women

Introduction

One of the most significant discussions across the world has been associated with the problems of hunger and malnutrition. The global vision for 2025 was a world free of hunger and malnutrition in all its forms. The Global Nutrition Report 2020¹ advocates for equity in nutrition. It highlights the need for equitable, nutritious, efficient, and inclusive food systems around the world.² Global Health Report (GHR, 2020) statistics show that one in nine people worldwide is undernourished, and one in three is overweight or obese. Of 194 economies, only eight are on track to achieve four of the ten global nutrition benchmarks of anaemia or an adult obesity-free country by 2025. The pattern is clear; development is too weak to meet the earth's goals. The progress of each country varies in the form of malnutrition based on factors such as money, geography, age, gender, and education, and these differences are exacerbated by conflict and other types of fragility. High-quality, detailed nutritional data is still lacking, but it suffices for further action.

Context of Women and Nutritional Status in the Global Scenario

According to the Global Multidimensional Poverty Index Report 2021³, of the 5.9 billion people in the 109 countries surveyed, more than one in five people (1.3 billion) live in multidimensional poverty. About 690 million (28.2percent) of the 2.4 billion people in 41 countries with ethnic, racial, and caste statistics live in multidimensional poverty. Within racial groups, inequality remains pervasive in many countries. One in six people living in multidimensional poverty lives in a female-headed/ matriarchal household.

¹Global Nutrition Report “Action on equity to end malnutrition”2020

²Power, privilege and priorities GLOBAL HEALTH 50/50 REPORT 2020

³Global Multidimensional Poverty Index 2021 Unmasking disparities by ethnicity, caste and gender

Women and Health, Especially Nutrition Status

Women's rights, roles, and health are affected by economic, environmental, social, political, and demographic changes with complex epidemiological shifts and increased care obligations. Although some areas of girls and women's health have improved markedly in the past, the situation continues to evolve. Decades later, there are still a large number of unsatisfied claims. Unfinished agendas in reproductive health, nutrition, communicable diseases, and emerging epidemics of chronic and non-communicable diseases must be effectively addressed simultaneously by health systems and societies to ensure that women's comprehensive health needs are satisfied throughout their lives. (The Lancet, 2015)

Health Issues of Tribals

Statistics show that one-third of the world's tribal and indigenous population, which is over 104 million tribal people, live in India, comprising 705 tribal groups accounting for 8.6 % of the country's population. National Family Health Survey (NFHS 3) shows that 65 % of tribal women and 77 % of tribal children suffer from anaemia. Access to health services becomes difficult as the roads are poor or restricted. Poor availability of health personnel, lack of adequate equipment, language, and social barriers, waiting time spent at health centres, and poverty also add to the problem of access. The paradox of vacant posts of doctors and specialists in the PHCs and CHCs in tribal areas and the non-enforcement of a bond on 90 % of doctors are inexplicable and tragic. While malnutrition and communicable diseases continue to be rampant, rapid urbanization, environmental disasters, and changing lifestyles have resulted in a rise in the prevalence of non-communicable diseases like cancer, diabetes, adding to this, is the third burden of addiction to substances and alcohol. Thus, the tribal population of our country faces a triple burden of diseases. (Bang, 2018).

Review of Literature

The literature reviewed aims to analyze the disparities as well as nutritional patterns emerging in different communities. Indigenous communities in India are the most impoverished and vulnerable in terms of disparities in social and health matters. This section provides a snapshot of the core debates around nutrition.

Structural Causes

Structural factors play a crucial role in addressing malnutrition. Mishra (2012) investigated how Gond tribes in Madhya Pradesh respond to both traditional healing and exogenous health management practices. The findings confirm a paradigm shift in terms of increase in the dependence on the modern health facilities and decline in the traditional healing practices. Capacitating the vaidus/ traditional healers and linking them with modern health institutions would create an integrating force between tribal masses and modern health practices.

Lal and Devanna (2016) highlight that socio economic impoverishment has been responsible in robbing the dignity of human beings.

Primitive and Ignorant

Several scholars have attributed 'Primitiveness and ignorance' as underlying causes of low nutritional status among women. Lenka, C (2016) opined that the tribal women in Mayurbhanj district of Odisha consumed three non-vegetarian meals per day. Their diet was found to be excess in energy, iron and calcium. These women who otherwise enjoyed good health were found to believe in black magic treatment and herbal treatment for getting relief from their illness which led to deterioration of their health status.

Research Methodology

Objectives of the Study

- To examine the dietary patterns of Warli women and identify the gaps in their eating habits.
- To ascertain the socio-cultural context of inadequate

nutrition with reference to the prenatal and postnatal care patterns.

Research Design

A Convergent Mixed Methods research design (Rubin & Babbie, 2016) was used for the study, in which the researcher collected qualitative data and quantitative data simultaneously and then analysed the data separately. The results of analysis were then merged to compare and confirm the findings of both the data sets. The study has been exploratory, descriptive, and explanatory in nature. A qualitative approach helped to delve deeper and analyse the factors that shape the experiences of the tribal women. The data on the socio-cultural context of malnourishment and the dietary pattern was studied using field stay, and five focussed group discussion through qualitative enquiry. The study has attempted to explore the causative factors of nutritional status of women and why it happens to women through five focussed group discussion with the important stakeholders/ key informants namely Accredited Social Health Activist (ASHA) Workers (2), Anganwadi Workers (2) and Elected women representatives (1). Qualitative methods supported in eliciting insights, experiences and recommendations for tribal communities.

Sampling Methods and Tools of data collection

Multi-stage stratified random sampling method was employed to arrive at the sample for the study. The selection process was done in four stages and is presented in chronological order: Palghar district was selected on the basis of density of tribal population (94%) as well as the prevalence of malnourishment among children and women, rate of life expectancy, infant mortality; and maternal mortality. Two Gram Panchayats: Savroli and Dongare, were selected for the study as they have officially been declared as prone to malnutrition, and the Government of Maharashtra has started Nutrition intervention in these villages. Eight types of tools were designed to capture the information from multiple stakeholders/key informants. The tools were first developed in English and then translated into Marathi which is close to the Warli

dialect. The following tools have been used in this study. Structured Interview Schedule was utilized to gather data from 310 tribal women. Anthropometric Measurement Tool to record the BMI of Warli women, 24-Hour Dietary Recall: was used to gather data about the food consumed by the respondent. Interview Schedule and Focussed Group Guideline with ASHA workers to gather data about their perspective on the health status of tribal women and the socio-cultural beliefs and practices regarding food. Focussed Group Guideline with Anganwadi Sevikas, Interview Schedule for Traditional Birth Attendant (TBA). Focussed Group Guideline for Elected Women Representatives (EWR) and Structured Interview Schedule for Government Officials.

Research Setting

The geographical scope of the study is confined to the Warli women in Savroli and Dongare Gram Panchayats of Palghar district in Maharashtra. The researcher immersed herself in the Warli community for a duration of six months, out of which three months were spent with a tribal family. The guidelines used for observation were: to understand the food habits of the tribal community in their day-to-day living situation, to understand the culture and traditions of the tribal community with specific reference to important events in women's development cycle, practices and traditions related to puberty, pregnancy, childbirth rituals, and the marriage ceremony. The field stay facilitated the process of building rapport with the members of the community. When the researcher communicated her desire to gather knowledge about the above checklist, they were receptive to the idea and reciprocated positively by providing information about the happenings in the village. Often more than two to five people informed the researcher about their ceremonies. Some even accompanied the researcher to the sight and provided valuable information related to the ceremonies.

Ethical Protocols

The following safeguards were employed to protect the informant's rights: The researcher made every effort to respect the dignity of the respondents throughout the research process. Before commencing the study, the researcher disclosed the purpose, aims and objectives of the study to the participants. Permission to participate in the study was obtained from the concerned authorities as well as the respondents. Oral informed consent was obtained prior to the beginning of the research and once again re-established during the research process. The respondents were hesitant to give written consent even though the informed consent forms were printed in Marathi and read out. The respondents were informed that they would not receive any benefits for participating in the study. Their participation in the study is voluntary, and they could withdraw their participation from the study at any given point in time. Confidentiality and anonymity were maintained during the process of the study. The respondents were thanked for their time and responses shared during data collection.

Origin of Warlis

The exact origin of what constitutes a tribe varies among anthropologists. Ethnologically the word Warli originated from 'Warud', which means forest or fanatic. Warli is an aboriginal tribe proficient in digging out roots and transplanting new trees in the forests and involved in agriculture. According to a Sanskriti kosa, Warlis were inhabitants of a region near Dharampur, which is described by Megasthenes as the Varalis. (Dandekar, 1998). According to Dr. Wilson, viral means a tilled patch of land; therefore, those who cultivated the patches of land are known as Warlis (Save 1945).

Profile of Warli tribals in Talasari

The Warlis have a unique lifestyle, food habits, customs, and traditions. They speak an unwritten Warli language, a mixture of the Khandesi Bhili dialect and Marathi. A small group of Warli speaks the Davar dialect, which is greatly influenced by Gujarati culture. A Warli appears thin and weak but has tremendous

stamina and can engage in laborious work. The majority of the Warlis have a wheatish complexion. Few Warlis have a fair complexion and light eyes due to cross-breeding with people of fair complexion. (Save 1945)

Sex Ratio (females per 1,000 males)

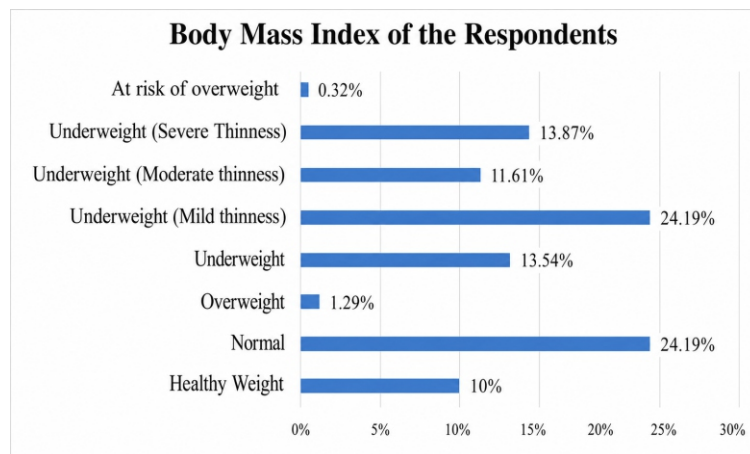
The sex ratio among the tribal population of the State was 922 in 2001, which increased by three points to 925 in 2011. According to the International Institute of Population Sciences (IIPS) published data, life expectancy at birth for tribals in India is 63.9 % against 67 years for the general population. (The Lancet 2016). As per NFHS 3, 21.1% of teenage tribal girls had begun childbearing. Anaemia is estimated to be responsible for 17- 46 % of cases of maternal deaths. The estimated Infant Mortality Rate (IMR) for the Scheduled tribe population in 2014 was 44.4%.

Tribal Health Culture Perspective

In tribal culture, health is viewed from a functional viewpoint. According to this perspective, a person is considered to be diseased only when his or her ability to perform his or her duties in life is wholly or partially affected. When this happens, people seek treatment influenced by the local culture specific to the area they live in. The functional perspective among tribals tends to neglect common ailments like fever, cold, and cough as it does not prevent their day-to-day activities/routines. (Mahapatra 1994; Kshatriya 2004). The health of the tribe is related to culture, environment, and social structure. It seems that in culture and medicine, the classification and aetiology of diseases are not separated from the "relation" of "health, disease, and medicine". *Magical Religious World*" (Kaushal 2004: 301-30). Overall, the tribals believe in four supernatural powers: 1) The safety spirits who always watch over them; 2) Benevolent spirit is often worshiped in the community and family to prevent sickness or death; 3) The malicious spirit: the spirit who has been given control over smallpox, fever, abortion ... 4) Lineage spirits: the forefathers' spirits who have constantly shielded them. (Sonowal et al. 2007). The tribals have a strong belief that illness is caused when the

above-mentioned spirits are disappointed with the individual, hence to please the spirit, magico- religious practices like incense sticks are burnt, ghee, candles, and offering of liquor/ meat to please God/disease-causing agents. Being close to nature, the tribals are heavily dependent on herbal medicine and resort to treating minor illnesses with the herbs found in their vicinity. (Sonowal, C.J. 2010)

FINDINGS OF THE STUDY



BMI Status of the Respondents

Along with the 24-hour dietary recall, the age, height and weight of the respondent was measured to receive the nutritional status of Warli women. The findings of the study were very disappointing. Only ten percent respondents had a healthy weight. Normal weight 24.19 %, Overweight 1.29 %, underweight 13.54 %, Underweight mild thinness 24.19%, Underweight with Moderate thinness 11.61 %, Underweight with Severe thinness 13.87%, at risk of overweight 0.32 %. The quality and quantity of food received in the first 1000 days of a child's life determines the nutritional status as well as the healthy growth of that individual. It creates an opportunity to grow, thrive and flourish. (Basanta Kumar Kar, Dec 2023)

Educational Attainment of the Respondent

Education opens doors of development and empowerment. The data indicates that 26.12 % respondents were illiterate; 23.54 % of them received primary education, 15.16 % studied up to the secondary level & 19.03 % passed the SSC. Beyond that, 14.19 % of them completed HSC and six of them pursued graduation. A small percentage of 1.93 % are graduates. The reasons for low education levels are the internal constraints of the accessibility, affordability, and availability debate.

Beliefs and Practices During Pregnancy

Registration of Pregnancy

Women are encouraged to register their pregnancy with the ASHA worker as well as the Anganwadi worker. Almost 77.74 % did not register their pregnancy during the first trimester. Only 22.25 % registered their pregnancy. One of the observations during fieldwork revealed that, among the Warli community, a majority of the miscarriages happen during the first trimester, hence registering pregnancy implies that community members will also receive information about the miscarriage.

Consumption of Folic Acid Tablets

An ASHA worker remarked “Often when we visit the women after delivery, we see packets of iron and folic acid tablets, kept safely on the kitchen shelf”. It has been noted that most of the tribal women throw away the iron and folic acid tablets. This clearly indicates the gap, i.e. although the tablets are supplied by the government, women do not consume them as per the requirement. Almost 76.77 % respondents reported, they consume folic acid and iron tablets during pregnancy. Those who do not consume iron tablets cited the following reasons: The tablets may lead to weight gain of the foetus and may have difficult delivery. Tablets are not tasty, it makes them feel satiated, besides it changes the colour of urine and stools. Thus, we find more and more malnourished children at birth.

Immunization during Pregnancy

Almost 76.45% received immunization during pregnancy. A quarter of them 23.54 % did not receive immunization during pregnancy as they were away at the maternal home or at work.

Beliefs Related to Women's Work Burden During Pregnancy Prohibited from cutting Onions

Women are not allowed to cut onions as it will reduce breast milk.

Sharp Object

Pregnant women are forbidden from cutting vegetables or firewood as they believe that using a knife or sharp instrument for cutting will harm the foetus's growth adversely. The child will be born with a cut / mark on one of its organs, especially the head.

Hair Bath

Pregnant women are not allowed to have a hair bath. It is believed that when a woman washes her hair in the afternoon or at night, the hair falls into the rakshas plate and this makes him angry and as a result a rakshas may be born.

Movements are restricted(Afternoon, evening and eclipse time)

During pregnancy women are not allowed to go out especially during noon time (12- 3 pm) and in the late evenings as there is a belief that the evil spirit (Cheda dev) will destroy the foetus, and the woman will have a miscarriage. Educated families do not allow pregnant women to lift heavy things and forbid them to work in the field. However, in some traditional families they believed that working in the field would lead to a smooth delivery, hence women were expected to work in the fields till the end of pregnancy.

Beliefs About Diet During Pregnancy

Diet during Pregnancy

Poverty limits options for the poor. The findings confirm that a

huge majority 77.41% consumed whatever was available. 18.06% remarked that they consumed iron, calcium and protein rich food. Many of them seemed to be ignorant about the importance of the nutritive value of foods, while the others were unable to access nutritious food due to resource crunch.

Deprivation of Fruits and certain vegetables

Women who have difficulty in conceiving after one year of marriage are taken to the Sorcerer (bhagat) to seek treatment. Often the Bhagat gives a big list of forbidden food items like fruits, especially Bananas, apples, coconut water, cucumber and all non-vegetarian items. These women are denied the foods prescribed by the Bhagat till the child is born. The couple is asked to make a vow, with the Bhagat and then after delivery the couple is expected to bring the newborn baby too and complete the vow and then start eating all the forbidden fruits, vegetables and also non-vegetarian food. During the Eclipse women are not given food till sunset.

“Don't eat stomach full, the babe in the womb will be crushed”. Hence women are not given sufficient food every day. Women are not allowed to eat well and are underfed, especially during pregnancy as the foetus will grow big and it will be difficult to conduct the delivery. Women did not eat fused bananas as it may cause twin pregnancy. The intricate process through which the information is transmitted is remarkable.

“Eating eggs during pregnancy will lead to stammering among children” (Participant voice). A popular belief among the Warli community is that eating eggs will lead to stammering hence pregnant women are deprived of eating eggs which is a good source of protein.

Women should be given apple and coconut water during pregnancy. Several women shared that apple and banana were purchased occasionally during their pregnancy as these are desirable and healthy foods. Women are forbidden to eat papaya up to the 6th month of pregnancy, as it is considered heaty.

Birthing Rituals in Warli Culture

Deliveries are held at the husband's house

Among the Warli community, the delivery is held at husband's home and the entire expenses are borne by the husband's family.

Hygiene

Women are provided hot water for bathing for about a month, soon after delivery. One of the respondent quotes” Women have bath regularly during this period”

Institutional Delivery

Mostly women are encouraged for institutional delivery. However, when the woman is being taken to the hospital, a common practise observed is that the traditional birth attendant is also requested to accompany the pregnant woman to the hospital. In most of the villages if the woman is unable to reach the hospital due to lack of transport facility or some other hurdles, the traditional birth attendant conducts the delivery there itself. The Traditional Birth Attendant remains in the hospital till the child is born and then returns home.

Rituals performed after birth

Among the Warli tribe a few rituals are performed after the birth of a child, namely: Dam dene, burying the placenta and Zoli diwas.

Daam Dene

To perform this ceremony the traditional birth attendant takes a thin iron rod or a thick needle and heats it and then it is placed two inches below the chest of the new-born child. This ritual or ceremony is called as “Daam Dene”. This ritual is performed as there is a belief that without the ritual the child may suffer from stomach diseases. Some also mentioned that this ritual makes the child strong to accept all the adversities of life.

Burying the Placenta is the completion of birthing journey of a child. The Traditional Birth Attendant is the main person who

performs all the rituals during this auspicious day. First of all, she takes the placenta of the new-born and buries it in a small pit prepared at the north side of the house. After placing the placenta, she puts few leaves of a specific plant and few grains of rice and recites a few mantras and then covers the hole with mud. A small stone was placed on the spot and a red (sindur) indicator applied to it. In the Warli community, placenta has a special significance during child birth at home as well as in the hospitals. The placenta is considered impure and therefore to be suppressed down in the earth otherwise it may harm the child. There are several traditions across the world especially in indigenous communities where placenta is the powerful element of childbirth. A similar practice is observed among the Australian (aboriginal) community too.

Zoli Diwas is an initiation ceremony conducted by the traditional birth attendant. Zoli diwas is the naming celebration organised by the family. If the child is a female, Zoli diwas is after four days, if it is a male child then on the fifth day. When asked why, one of the tribal teachers responded that girls are smarter than boys and hence mature faster. After delivery, on this day, the new born's mother too receives her first meal comprising plain rice and roasted Bombay duck. From now onwards she would begin eating her food as per the Warli culture. During lactation period, she is given boiled vegetarian food for about a month till the umbilical cord is dried and healed. Spices are included in the diet after one month. No special food is given to the mother. In fact, the nutrition provided by the anganwadi is shared by all the family members.

Household Chores

Depending on the financial situation of the family, after delivery the tribal woman rests for about one to five days. The maternal grandmother of the child is invited to assist the new mother for few days in household chores. If there is no help, the new mother continues with the household chores and childcare responsibility. Women are expected to do all the chores related to the child from the time the child is born. Bathing the child, washing the clothes of the child, changing nappies, feeding, putting the child to sleep ...

Nurturing duties are not considered as work. In some cases, if the delivery is through C –Section then 15 days to one month's rest is permissible for women. Women who deliver during the monsoon season are expected to assist in agricultural work also. Feminists philosophize that maternity should be considered as work and women should even be paid wages.

Challenges Faced by Mothers

First time mothers face a lot of challenges with regard to feeding the baby such as holding the baby in the right position while breast feeding.

Initiation and duration of breastfeeding

Breastfeeding begins immediately after birth and continues upto three years in some cases. Women who do not have sufficient milk give cow's milk as a substitute to the child.

Care of the baby's umbilical cord

During one of the interviews a respondent shared that after delivery, she would take an old cloth and burn it and put the ash into the child's navel and wrap an old cloth on the stomach to protect the infant from infection.

Preference for birth at home rather than institutional birth

During my fieldwork stay in the villages, I learnt that most of the villages do not have access to adequate roads and transport facilities. Women who suffer labor pains especially during the night have no other alternative than choosing to conduct delivery at home.

Social Work Implications

Tackling malnutrition requires political will and commitment, collaboration across all sectors, and significant investment in data for program implementation and progress assessment needs to be explored. Women need to take leadership in ensuring that adequate amount of fund is allocated towards fulfilling the nutritional needs of the communities that are most affected. There

is a need to invest in nutrition especially for the resource crunched communities.

Cases related to malnutrition, caste discrimination, exploitation by the landlords or brickkiln employers need to be documented and addressed to restore justice to the people.

Fieldwork revealed that not a single village had access to public amenities. It is proposed that all the hamlets should have at least basic public amenities including water, roads, electricity, public transport and sanitation facilities. This should be on a priority list.

The schemes related to water supply need to be routed through appropriate channels. This will help people to access potable water for drinking, domestic chores, livestock as well as farming. A good number of people possess land but cannot cultivate a second crop due to scarcity of water. Access to clean water will also resolve the issues related to personal hygiene and sanitation.

Warli diet is carbohydrate focussed and protein/ vitamin and micronutrient deficient. Restoring their original diet which was with millet will enhance their health status.

Evidence based interventions need to be promulgated. Tribals have a rich resource of indigenous knowledge of herbs, plants roots that are effective in healing. Preserving and propagating the use of traditional medicines is the need of the hour.

Not a single respondent had a planned diet during pregnancy. A huge majority consumed whatever was available. It is recommended that women receive a balanced diet during pregnancy. It is the State's responsibility to ensure this.

After delivery Warli women should be given proper food with green veggies, soups, fruits and milk to regain her health. Behaviour change is essential among elderly women, who promote the traditional beliefs of prohibiting women from having meals.

Food for work programme needs to be introduced in villages where there is absolute poverty. Grain banks need to be established, so that people have access to food during lean periods and people do not die of hunger.

Following the example of an NGO, SEARCH, 'Tribal Health Assembly' needs to be organised at district level. This includes representatives from all sectors. The purpose of this assembly would be to listen and understand the health problems and priorities of people, to receive approval on the proposed health activities and obtain feedback on the ongoing activities.

Conclusion

Indigenous communities in India are the most impoverished and vulnerable in terms of disparities in social and health matters. Fieldwork experience provided a glimpse of how the beliefs are practiced and transmitted to the next generation without questioning their scientific temper. Special attention needs to be given to the policies that govern their lives, making women active partners in decision making to ensure that women's comprehensive health needs are met throughout their lives. Through this study, the researcher hopes to represent the feeble voices of the tribal women, which are silenced by the powerful within their community.

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IDENTITY, MARGINALIZATION, AND HEALTH CONSEQUENCES IN TEA GARDENS OF ASSAM

Balaka Chattaraj¹

Abstract

The Adivasi population in Assam was forcefully migrated by the British planters in the early 19th century after the establishment of the tea estate. The laborers were settled within the tea estate and they were victims of brutal violence such as beating black and blue, underpayment of wages and filthy living conditions. It pushed them towards prolonged poverty and poor health consequences. Even after Independence and the 1951 Plantation Labor Act, the ownership of the garden changed from British planters to Indian private companies. However, the condition of the laborers remained the same. This paper intends to highlight the issue of identity, marginalization, and health consequences faced by the laborers presently, using primary data collected through in-depth interviews.

Keywords: Adivasi, Health, Tea Estate, Identity, Marginalization.

Introduction

Historical establishment of the Plantation

The Plantation industry all over the world was an important industry before and during the time of the Industrial Revolution. ILO defines Plantation as a group of people or political unit which was formed by the British colonial rule particularly in geographic locations such as North America and West Indies for agricultural purposes. (ILO, 1950). The spread of British colonialism in Africa and Asia has added a deeper connotation to the term plantation. The plantation crops that were grown in particular geographic locations are cotton and sugarcane in the Caribbean islands, of

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Mauritius and Fiji, Tobacco in the Southern United States and Indonesia, Tea in China, Indonesia and India and cocoa in Ghana.

The colonial government required two things for the establishment of plantations in colonized areas: a large plot of land and cheap laborers, but the area was sparsely populated and the colonial planters avoided employing the local population due to resistance and better power of bargaining among the laborers. So began the slave trade, the trading of laborers from various parts of Africa and Asia and employing them in plantations. The cotton plantations in the Southern United States, the sugar plantations in Caribbean islands and other places such as Guyana, Mauritius, and Fiji were all run on slave labor from Africa in the early stages. The easy availability of cheap labor made the colonizers plan for the next move, which was to keep the laborers under complete control. Henceforth the plantation was not known just by its resident labor force but as the force of "Alien origin". (Graves, 1959, 115). The slave trade was a lucrative business. It entitled the Europeans to capture the Africans and bundle them off to the plantations in different parts of the world. The trade was initiated by Spain; later Britain took over the major part. Ron Ramdin a Caribbean historian said "European enterprise and slavery during the seventeenth and eighteenth centuries and also the greater part of the nineteenth century, were closely connected, helping the spectacular rise of British, French and Spanish ports such as Bristol, Liverpool Nantes, Bordeaux and Serville" (Ramdin, 2003). Christopher Hills argued "where did the capital for the Industrial Revolution come from? Spectacularly large sums flowed into England from overseas – from the slave trade and especially from the 1760s organized looting of India" (Hills, 1983). Britain and France banned the slave trade in the middle of the nineteenth century. The end of the slave trade marked the beginning of the indenture system of labor. Under this system, the workers had to agree to serve the plantation for a specified period and then they would be free to return to their home This system had improved as compared to the slavery system as it was no longer a lifetime commitment. After the contract was over, they were

allowed to return to their home. The main problem however, was that under the indenture system, the workers were paid much less, so they were unable to save and return to their families. With no place to go even after the contract ended, they continued to stay in the plantation area. The basic ethnic difference between slave labor and indentured labor was that the slave laborers were African and the indentured laborers were mostly Asians. The system of indentured labor employed mostly the Indian-origin laborers and they were mainly from the poorest section of society.

Plantation labour history in India

The East India Company had a monopoly on the tea trade with China. But Post-Opium War, the trade with China was cancelled. In 1839, Robert Bruce discovered the potentiality of Assam's land to grow tea (Dasgupta, 1986). The establishment of tea plantations requires a large number of workers, but the districts such as Lakhimpur, Kheri and Sibsagar were sparsely populated, Initially, the East India Company forced the local tribal population to work, but they refused as it is labour-intensive work (Guha, 1977). So, the East India Company adopted the measure to forcefully migrate the tribal communities, mostly comprising Santhal, Munda, Kharia, from present-day central Indian states such as Jharkhand, Chhattisgarh, West Bengal, Bihar, and Odisha. The East India Company employed middlemen, also known as "arkatis" who used violence, coercion and tricks in the name of employment, to forcefully migrate the labourers to Assam and employ them in tea estates. They were extremely brutal and often beat the labourers black and blue if they denied working or tried to escape from the place which earned them the term of "man-eating tigers" (Das, 1931). The Company adopted an indenture labour system. According to the indenture labour system, the workers were employed for a five-year contract, and then they were allowed to leave. In 1859 the East India Company passed the Worker's Breach of Contract Act. It stated that the workers were eligible to be punished if they escaped the workplace. Additionally, the workers were paid so little that it was impossible for them to return to their native region after the contract was over (Das, 1931). They were

kept in subhuman conditions and were denied basic human rights such as decent living conditions, just wages and education. The workers suffered from food scarcity, poverty and low wages and were settled in suffocating conditions which resulted in health conditions such as tuberculosis, cholera, typhoid, dysentery and reproductive health issues (Bhowmik, 2011).

Plantation labour conditions Post-Independence

After independence the ownership of the plantation companies shifted from British tea planters to the Indian companies. The Plantation Labour Act was passed in 1951, which made it compulsory for the employer to provide education, health and better living conditions to the workers. So, in every tea estate it was compulsory to have a primary school, health centre and quarters for the workers (Bhowmik, 2011). However, it was recognised that from Post-Independence to the present situation, the conditions of the school, quarters and health centre are extremely poor (Timung & Sarmah, 2013). The workers and their families suffer from illiteracy, crowded living conditions, and unhygienic neighbours. They are paid extremely low wages and suffer from chronic poverty. Socio-economic conditions such as illiteracy, crowded living conditions, food scarcity and poverty lead to poor health situations. These workers often suffer from malnutrition, tuberculosis, reproductive health issues and anaemia (Timung & Sarmah, 2013).

Post - Independence it was recognised that the community mostly comprised of diverse tribal/Adivasis such as Santhal, Munda, and Kharia, but it also included Dalit communities such as Tanti (mostly from Odisha) and Dom. The government therefore termed the community the “tea tribe”. The population, due to historical marginalisation and strict surveillance, mostly stays inside the tea estate. Due to their migration status, the community finds it difficult to assimilate with the larger Assamese population (Bhowmik, 2011). Other than suffering from poverty, malnutrition, and poor living conditions, they are the victims of discrimination due to their Adivasi, migrant, and labour status

(Bhowmik, 2011). The workers mostly stay inside the tea estate and work. The only entertainment is meeting with fellow workers who consume alcohol for relaxation. So, alcoholism is a big issue, and it also influences poor health conditions among the workers, such as tuberculosis and hypertension

Literature identifies the historical marginalisation of the community, their present poor situation and their poor health conditions. However, there is a gap in understanding the historical marginalisation and discrimination of the community in the present day and its effect on the health conditions of the workers. Therefore, the present study aims to study the historical marginalisation of the community, violation of their basic rights and the present health condition of the workers.

Research Methodology

Research design

The study is qualitative. The qualitative methodology was adopted to understand the detailed description and perspective of the community about their own history as well as the present socio-economic political condition and its effect on their health condition. The study tries to capture the experience of the workers and their emic perspective through in-depth interviews.

Research Universe

The researcher selected four tea estates – Dhekiadhuli, Sirajhuli, Addabarie and Sessa tea estates – from Sonitpur district. The particular four tea estates were selected understanding the surveillance nature of tea estates. Since tea estates in the present day are recognised as private property, they do not allow outsiders to enter the area and converse with the workers. The researcher applied to six tea estates for permission to conduct the study and permission was granted by all six. All four tea estates are single-owned private tea estates.

Sampling Strategy

The researcher selected a purposive sampling strategy and

intentionally selected the Activists from the AASAA (All Adivasi Student Association of Assam) organisation to narrate the historical context of the community and the present socio-economic-political situation of the workers. In-depth interviews were conducted with three AASAA Activists from the Dhekiajhuli and Sirajhuli tea estates. The researcher selected five TB patients and five other workers suffering from reproductive health issues, hypertension, anaemia, and malnutrition to understand the present health condition of the workers. In-depth interviews were conducted with thirteen participants, including workers and Activists, to understand the experience, emic perspective and situation of the community.

Data collection tools and technique

The researcher used two different sets of interview guides to interview the AASAA Activists and the workers suffering from poor health conditions. The questions mostly included the history of the tea estate, the perspective of the community people about it, the present socio-economic-political situation of the workers, the difficulties in assimilating with the larger Assamese population and the general apathy experienced by the community. The interview guide for the workers suffering from poor health conditions includes their wages, living conditions and conditions of the health care centre.

Findings of the study

The findings of the study are presented in three different themes i.e. Identity and marginalization of laborers in the tea gardens of Assam, the present socio-economic-political situation of the workers and the health condition of the workers.

Identity and marginalization of laborers in tea gardens of Assam

Denial of ST status

Post-independence and the Plantation Act of 1951 did not end the misery of the tea estate workers. In the interviews, the AASAA

Activists mentioned that the community people were denied 'ST status' by the State. The participants highlighted that despite the majority of the workers belonging to the Adivasi community, they were denied 'ST status'. The community was labelled as 'tea tribe'. The participants mentioned that the denial of 'ST status' and being labelled as 'tea tribe' was stripping the community of its ethnic identity and labelling them with a term based on their forced occupation. The Post-Mandal Commission granted 'OBC status' to the community. Many Activists stated that despite their being ethnically Adivasi and a historically marginalised community, they cannot receive the benefits of ST status for employment and higher education. It is one of the major reasons that the marginalised community is further pushed into economic marginalisation.

The participants mentioned, “We are Adivasi yet denied ST status due to our migrant status. Our ancestors were forcefully migrated. We are victims of brutal colonialism. But Post-Independence, the State denied us ST status, meaning we are denied the benefits of reservation meant for the upliftment of the marginalised tribal communities. In Assam we have been victims of ethnic conflict and poverty and economic marginalisation, despite the fact we are not at the receiving end of reservation benefits.”

Denial of land rights

The community is denied land rights known as “mati ka patta”. The Activists mentioned that despite their ancestors living on the land and working in tea estates, contributing to the State economy, they are not granted land rights. The population living on the land generationally has no rights over the land. They live in the quarters granted to them. The workers are permitted to stay in these quarters as long as anyone from the family works in the tea estate. Most of the time people transfer the job in the tea estate from one generation to another to safeguard the living quarters. They are paid extremely low wages, which makes it difficult for the workers to shift elsewhere. However, the new generation is trying to save their PF amount so that they can move to a nearby village and their children will not be obliged to work in the tea estate.

A participant mentioned, “We lack land rights. We can stay in the quarters as long as we work. So, to safeguard the quarters, most of the people work in the tea estate. At every election, different political parties promise they will grant us land rights, but they fail to deliver this promise post-election”.

Agitation and consequences

In 1996, the community faced the Bodo-Adivasi conflict. The participants narrated that the conflict and consequences inspired a few people from the community to assemble together and form AASAA (All Adivasi Student Association of Assam) in 1999. The Association has a history of organising protest and agitation peacefully to demand ST status and to improve the condition of the Adivasi workers in Assam. In 2007, they assembled in Guwahati to protest near the State legislature but the community met with violence and repression. A prominent woman Activist from the community was stripped and beaten. The violent repression of the protest has set back the morale of the community. This incident is casually mentioned in *Pratidin* news, 2007. Next, the AASAA also called for protest under the slogan “no ST, no vote”. But the organisation met with external interference from political parties, bribery and pressure that later sabotaged the agitation. The other organisations which are predominant in the tea estates of Assam are ACMS (Assam Chai Majdoor Sangh) and ATTSA (Assam Tea Tribe Student Association). The Activists narrated that often all three organisations differ with each other ideologically rather than choosing to unite with each other. People narrated their disappointment at this situation.

The narration reveals the suppression of protest and agitation, the denial of land rights on the land they have been working for generations, the denial of ST status by labelling the community as a 'tea tribe', which is perceived as stripping them of their aboriginal ethnic identity thus depriving them of the benefits of education and employment.

Present situation of the tea estate

Low wage payment

The workers and the Activists interviewed narrated that from Post-Independence to contemporary times, the workers are paid extremely low wages. Previously they were paid Rs. 162/-. Post protest and agitation, the wages of the workers in 2022 were increased to Rs. 232/- and presently the workers are paid Rs. 250/- from which Rs. 50/- is deducted for PF. The low wages make workers unable to meet their basic household expenditures. They also narrated that usually they eat rice which is available from the ration shop, and for vegetables they depend on the nearby market. They are unable to eat eggs, fish, meat or other nutritious food due to low wages. Poor nutrition causes health problems such as anaemia, malnutrition, vitamin deficiency.

Uncertain living situation

Extreme low wages often make the workers dependent on everyday work. They narrated that they work in strict surveillance. They are compelled to begin work by 7:00 A.M. and terminate at 4:00 P.M. in summer. They get a lunch break from 1:00 PM to 2:00 PM. If they are late for work, they are sent back home and they lose their daily wage which is also dependent on the target of the day. The workers have to pluck 22 kg of tea leaves; if they fail to do so, their wages are deducted. So, the workers narrated that they work under extremely stressful situations. Low wages and the remote location of the tea estate make it difficult to leave the tea estate. In their leisure time, they consume alcohol which is mostly homemade and available at a cheap rate. In tea estates therefore, irrespective of gender, consumption of alcohol is an issue. Chronic alcohol consumption affects their health conditions. The workers narrated that though they know alcohol is harmful for health, they still consume it, as it is an escape from boredom and stressful work situations. Many workers termed their life condition as 'uncertain' and narrated their helplessness, inability to escape their situation and lack of personal growth in the given conditions. Many workers narrated that though they want their children to be educated, it was difficult for them to put their children in private

schools. Education conditions in the schools of the tea estate are extremely poor and many even narrated that if they put their children in private schools, their economic situation forces the children to drop out of school.

Health Problem faced by the workers

The workers revealed that the major health problems they face in the tea estate are hypertension, tuberculosis, liver infection, worm infestation, anaemia, vitamin deficiency, and reproductive health issues. The problems that cause a health crisis are crowded living condition, malnutrition, poverty and lack of access to health care facilities. Due to lack of awareness about health conditions, they often ignore the early symptoms of any health crisis and are later diagnosed with chronic health problems. The TB patients narrated that since TB is a communicable disease the management takes it more seriously than any other disease. Accordingly, TB patients receive treatment from the tea garden health centre.

Multi-drug resistant TB patients however who need to continue treatment for three years, have to go to the district health centre where medicine is distributed on specific days. Lack of transportation often causes them to discontinue treatment.

Interrupting medication allows stronger bacteria to survive and risk infecting others.

Alcoholism causes liver and kidney damage. The tea estate health care centre has a lack of rehabilitation programmes for the workers suffering from alcohol addiction.

Discussion and Conclusion

Bhowmik (2011) stated that the tea estate workers were forcefully migrated. They were settled inside the tea garden and denied human rights during the colonial period. The marginalisation further affected their health conditions. Post-Independence, despite several measures, tea garden workers in Assam continue to suffer from illiteracy, unhygienic living and working conditions, poverty, low wages and malnutrition (Timung & Sharma, 2013). Deb (2000) revealed that social exclusion, low wages and poverty are mainly responsible for health problems in the Assam tea

estates. The researcher realised that though the tea estate workers are non-vegetarian, yet they only consume rice, potato and salt as their daily diet due to low wages and poor purchasing power, which result in their malnutrition and chronic weakness. Social exclusion, a toxic work culture, and constant surveillance also cause the workers to adopt risky lifestyle behaviours such as the consumption of homemade alcohol and adding salt to tea, thus bringing on themselves health problems such as hypertension and tuberculosis (Hazarika et al., 2002; Hazarika et al., 2015). Residing in crowded living conditions with no potable water or decent toilets, the workers often suffer from filariasis, worm infection and jaundice, (Medhi et al., 2006; Medhi et al., 2007). The present study argues that the tea estate workers find it challenging to assimilate with the larger Assamese culture. They are historically marginalised and continue to be discriminated against, thus rendering them socio-economic and politically marginalized.

Recommendation from the perspective of social work

Social work practice involves awareness programmes and campaigns against poor health outcomes. The IEC (information, education, communication) programmes focus on encouraging people to undertake treatment, identify early symptoms, improve dietary intake, and maintain cleanliness. However, the programmes find it challenging in socio-economic marginalised communities such as the tribal belt since they have different cultures, histories and perspectives. Social work practice, including campaigns and programmes, must undertake the holistic approach of understanding the historical marginalisation of the community, such as workers in the tea estates. It must understand the colonial brutalisation towards the community and the colonial legacy continuing still in the contemporary period. It must undertake and adopt a decolonial and inclusive approach for promoting health and wellness in tribal belts.

Social work research must understand the complex history of this community and their positionality in the present day and work towards a decolonial and inclusive health campaign. The workers'

demands should be facilitated in terms of education, nutrition, better living conditions, proper work facilities and improving the conditions of the existing health care centre. The collaboration of Social workers, the Tea-estate workers and the Management through advocacy, negotiation and campaign is required for enabling their overall access to their human rights.

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**REFRAMING CKD CARE IN INDIA: AN
APPLICATION OF SEGMENTED MULTISECTORAL
MEDICAL SOCIAL WORK APPROACH**

Ms Sharvari Pawar¹

Abstract

Chronic Kidney Disease (CKD) is an emerging health issue in India, with the number of patients doubling in the last twenty years. As a chronic condition, it profoundly impacts the health and welfare of patients and their caregivers. This paper argues for strengthening existing medical social work practices for patients with chronic kidney disease. It underscores the need to use appropriate research strategies, models for formulating interventions and guiding policies. Drawing upon primary data, a mixed-method design was used under which 52 respondents (i.e., including 26 dialysis patients and their caregivers) were surveyed. Key informant interviews were conducted with hospital personnel and a medical social worker. Open coding was conducted during data analysis. Situated within the theoretical framework of the socio-ecological model of health, the analysis encompasses individual, interpersonal, organizational, community, and policy dimensions. The research findings revealed that diabetes and hypertension are common comorbidities with a higher prevalence of CKD rates amongst older dialysis patients. Apart from patients, caregivers remain invisible to the system. The data reveal that the majority of caregivers faced challenges, including balancing work and patient care. They often encounter stressors such as a lack of financial security, unemployment, emotional, and mental turmoil. The data findings revealed that the majority of patients and caregivers primarily expect financial assistance and an expedited administrative and funding allocation process followed by psychosocial support from the medical social worker.

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Keywords: Dialysis patients, Caregivers, Chronic kidney disease, Medical social work.

Introduction

Health is an important asset that encompasses all aspects of physical, mental, spiritual and social well-being (Park, 2023). In the Indian health landscape, there has been a notable rise in non-communicable diseases (NCDs) over the past 10 years (Kastor & Mohanty, 2018; Mahal et al., 2010; Van Minh et al., 2013). NCDs account for 65% of all fatalities in India (GOI, NFHS statistics 2019–2021). At the World Health Summit in 2023, the Ministry of Health and Family Welfare emphasized the importance of a comprehensive strategy that includes early discussion, preventive measures, and efficient management to reduce the prevalence and impact of NCDs on citizens' well-being. The 75/25 project aimed to screen and treat 75 million patients with diabetes and hypertension with standard care by 2025 (Government of India, 2023). However, Chronic Kidney Disease (CKD), an emerging health disease, falling under the spectrum of NCDs, received less attention and was considered a marginal issue. Patients with CKD are deprived of adequate health services, as it is not included under non-communicable disease initiatives (Bharathi & Jha, 2020).

Kidneys serve as filters for our bodies; they are multifunctional, powerful chemical factories that also produce hormones that affect how other organs function (Raghavendra, Mallikarjun and Vidya, 2013). Any hindrance in the functioning of these organs, affect the overall functioning of the body. As per Kashy (2016), there has been a twofold increase in the number of Indians diagnosed with chronic renal illnesses in the past twenty years.

The exact disease burden of CKD remains untapped due to unavailability of data in the Indian CKD registry system. The number of patients receiving dialysis in India is growing by 10% to 15% annually. It is estimated that 800 persons per million (pmp) in India have chronic renal disease (Kashy, 2016). Typically, more than 850 million individuals worldwide suffer with CKD, making

it the sixth leading cause of death by the year 2040. (Oostram Taj and Dorgelo A, 2022). In the context of India, kidney failure is becoming more common, where each year over 210,000 new cases are being identified (Raghavan and Anand,2023). Nevertheless, the recent Pradhan Mantri National Dialysis Program launched in the year 2021 offers some hope in reducing end-stage kidney failure cases in the country.

In this research paper, the author sheds light upon the severity of Chronic kidney disease, existing medical social work practices, and the issues, needs, and challenges of patients and their caregivers. Using a mixed-methods approach, the author presents the voices of patients and their caregivers. In the following section, the author describes the prevalence and magnitude of kidney disease along with available interventions for managing CKD in India, followed by the theoretical framework, research methodology and research findings. In the conclusion, the author proposes intervention and policy recommendations.

Prevalence and Magnitude of Kidney Disease

India has largest disease burden of Diabetes as compared to other countries, the projected figure being 57.2 million cases in 2025 (Pradeepa, Deepa and Mohan, 2002). Similarly, number of people with hypertension was expected to double from the year 2000 to 2025 (Chockalingam, Campbell and Fodor, 2006). According to Rajapurkar and Dabhi (2010), both of these illnesses serve as comorbidity factors for renal disease, making India the country with the highest prevalence of chronic kidney disease. Major risk factors include diabetes, high blood pressure, family history of kidney failure, and the elderly population being 60 years and older (kidney.org, N.D)

According to estimates from 2018, there were roughly 175,000 chronic dialysis patients in India, translating to a prevalence of 129 per million people (Bharathi and Jha, 2020). Compared to the rest of the world, India's dialysis demand is growing at 31 percent (Ookalkar, 2023). In the year 2023, India had the world's second-

highest chronic kidney disease patients, amounting to an estimated 138 million adults affected by the condition (NDTV Health 2025). In the last two decades, the country has been slowly shifting towards becoming the next CKD capital. This is alarming due to the lack of available health resources in the country. The next section covers this in detail.

Available Interventions for Managing CKD In India

The cases of CKD in India are often diagnosed late due to the lack of awareness (Rajapurkar et al., 2012). Kidney disease can be prevented by understanding its six warning signs (National Kidney Foundation, <https://www.kidney.org/>):

- i. Elevated blood pressure
- ii. Urine that contains blood or protein.
- iii. Blood tests with creatinine and blood urea nitrogen (BUN) that are not within normal limits. Waste products that accumulate in the blood when renal function is compromised include BUN and creatinine.
- iv. A GFR (glomerular filtration rate) of under 60. GFR is a renal function metric.
- v. More frequent urination, particularly at night; difficult or painful urination.
- vi. Hand and foot edema, puffiness around the eyes.

The treatment for kidney failure includes haemodialysis, peritoneal dialysis or kidney transplantation. Haemodialysis (artificial kidney) is usually performed thrice a week at a dialysis unit or home. A study on the "Economics of dialysis in India" by the Mumbai Kidney Foundation revealed that there are around 950 nephrologists (not all ISN members) and 700 dialysis clinics in India, with the majority of the 4000 dialysis machines being located in private healthcare facilities and cities (Khanna, 2009). India had about 13,000 dialysis facilities as of 2018. An additional 8000 dialysis stations at government hospitals or through the private-public partnership (PPP) model have been added by the National Dialysis Program, which was established in 2016 to serve dialysis patients from low-income households. However,

with an estimated 1.75 million ESKD patients in India (Konnur et al., 2024), the dialysis need is not entirely met.

In India, 170 accredited transplant centers undertake 3500 kidney transplants a year, taking into account government transplant centers. The cost of a single haemodialysis (HD) session in Indian government hospitals ranges from INR 150 to Rs 2000. Most private hospitals charge an average of INR 12,000 per month for HD and Rs 1,40,000 per year for dialysis (Khanna, 2017). Deliberate neglect and patient rejection have occurred in the context of CKD treatment in India (Raghavan et al 2023). They often default on the treatment process due to financial constraints (Agarwal, 2005). Though the government of India offers dialysis through various schemes there is discontinuation by a few as their livelihood is based on daily wages (Shaikh et al, 2018). One of the primary steps is to include Chronic Kidney Disease in policy discourses and under the spectrum of Non- Communicable Disease Programmes (Jha, 2020). Similarly proper quality management and accreditation of dialysis centres and hospitals is crucial. The standard for dialysis facility covers various aspects related to patient care in these facilities: Governance, Leadership, Human resources, Safety, Facility management, Patient Care, Pre-dialysis, Post-dialysis care, Water treatment, Infection control, Record keeping, Patient rights and Responsibilities, Education. (Ookalkar, 2023). A study conducted by Koonor et al. (2024) on dialysis practices across India argues that, as the PPP (Public-Private Partnership) model of dialysis delivery has replaced privately operated dialysis facilities, the majority of dialysis facilities now have a quality-control system in place.

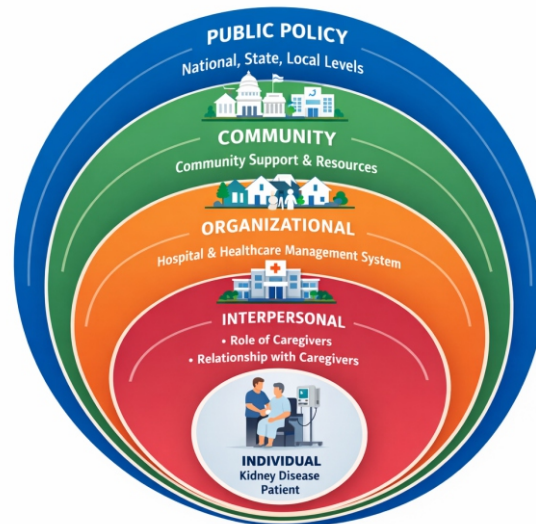
The next section presents the study's thematic framework, followed by the research findings.

Theoretical Framework

The socio-ecological model (SEM), initially formulated by Urie Bronfenbrenner in the 1970s, was designed to comprehend human development within a framework of interconnected

environmental contexts. In the 1980s, this framework was developed into a formal theoretical model. The SEM is usually represented as a series of circles around the person, with the person in the middle and the systems surrounding them. The microsystem consists of the immediate environments in which an individual directly interacts, encompassing close relationships and daily interactions, thus representing the most proximal and influential context. The mesosystem includes the links between these immediate settings, such as those between family, school, work, and neighborhood. The exosystem includes larger social structures that have no direct impact on individuals but do shape their experiences in other ways, such as through community structures and social networks. The macrosystem is the larger social, cultural, economic, and ideological framework that shapes and affects the other systems. These include things like cultural values, societal norms, and belief systems. Lastly, the chronosystem includes the time dimension, which accounts for changes in a person's life, historical contexts, and, in more recent versions, the effects of policy environments.

The SEM proposes that health outcomes are influenced by the dynamic interplay between individual attributes and the broader environmental context, encompassing physical, social, and political dimensions. The Centers for Disease Control and Prevention have modified the SEM for health promotion, focusing on various interconnected levels of influence: individual, interpersonal, organizational, community, and policy. The socio-ecological model emphasizes that health determinants function at various levels; thus, effective interventions must be designed to address these interconnected layers concurrently.



(Source : OpenAI. Socio-ecological model of health- Kidney Disease, adapted from Centers for Disease Control. 2026. ChatGPT, AI-generated image)

The socio-ecological model has been extensively utilized in health promotion and disease control initiatives. In the current study, the researcher utilizes this model as a theoretical framework to guide her analysis. The SEM elucidates the various interconnected levels of influence that determine health outcomes, emphasizing the interactions among individual, interpersonal, organizational, community, and policy-level factors. It thus offers a holistic perspective for analyzing the intricate factors that underpin and guide health promotion and intervention strategies for CKD patients and their caregivers.

Research Objectives

1. To understand the needs, challenges, and issues of dialysis (CKD) patients and their caregivers.
2. To understand the role of the interdisciplinary team of the hospital in navigating health services for dialysis patients.
3. To apply research methods for interlinking and mobilizing resources for dialysis patients and caregivers in the hospital settings of Mumbai

Research Methodology

In the present study, the author followed a mixed-methods approach situated in Kurt Lewin's (1964) action-oriented research process model. Typically, this model provides a platform for the researcher to change the system while simultaneously generating critical knowledge about it (Adelman, 1993). Lewin's model organizes the research process into four stages: planning, action, observation, and reflection. The mixed-methods approach, on the other hand, makes it easier to collect and combine qualitative and quantitative data systematically at each stage of the research process. This facilitates a thorough comprehension of the research problem while simultaneously guiding contextually pertinent interventions.

The research was conducted while the author served as a medical social work intern at a charitable trust hospital in Mumbai. During her fieldwork internship in the hospital (2017-2018), she spent most of her time in the dialysis ward with patients and their caregivers. She visited the dialysis ward twice a week over a period of one year. Her role in the dialysis ward was that of a medical social work intern, the positionality of an outsider. The identification of the research problem and the selection of methodology resulted from this iterative process of field engagement, encompassing informal conversations with the patients and their caregivers, fieldwork observations, and her experience as a medical social work intern.

During the planning phase, both qualitative (informal interactions and field observations) and quantitative (patient and caregiver baseline profiling) data were used to identify primary concerns. During the action phase, the researcher interacted with the field setting in a manner appropriate to her role as a social work intern. During the observation phase, data were systematically gathered through a semi-structured questionnaire, yielding both quantitative and qualitative responses. Furthermore, key informant interviews were performed with members of the hospital's interdisciplinary team to enhance contextual

understanding. The study included 52 participants: 26 dialysis patients and their caregivers. The incorporation of mixed methods into Lewin's cyclical framework enhanced analytical depth, bolstered the validity of findings through triangulation, and facilitated the emergence of grounded, contextually relevant insights.



(Source : OpenAI.Kurt Lewin's Action Research Model theory .
2026. ChatGPT, AI-generated image)

Sampling strategy

A purposive sampling strategy was employed for both qualitative and quantitative components.

Ethical considerations

The author obtained prior informed consent and interviewed only those willing to participate. Particular care was taken to ensure that participants were not overburdened; interactions were conducted in an informal and non-intrusive manner. For patients undergoing dialysis, interviews were scheduled before the procedure, during their waiting time, to minimize physical and psychological stress. Caregivers were similarly approached during waiting periods within the hospital setting. As a good rapport developed over a period of one year, trust and a bond were built between the researcher, the patients and caregivers.

To avoid countertransference, the researcher wrote her thoughts in a diary and worked every day with objectivity. As a medical social work intern, she had to maintain the hospital's conduct standards, follow protocols, and always exhibit professional boundaries.

In the initial phase, the researcher faced an ethical dilemma: the topic being sensitive, could evoke unpleasant memories associated with the ailment. However, she navigated it by building rapport and bonding, more as a friendly visitor than just a medical social work intern.

The qualitative interviews were informal and were noted. The surveys were conducted with caregivers, during which the researcher asked the questions and recorded their responses. In-depth interviews were deliberately omitted to avoid exerting pressure on the patients and their caregivers as they were already exhausted by waiting in long queues, and undergoing dialysis. It was important to adopt a trauma-informed approach, so informal conversations were conducted rather than in-depth interviews.

Data analysis and validation procedures

Data were analyzed using a convergent triangulation design within the mixed-methods framework. Quantitative data obtained through the survey were entered and analyzed using the Statistical

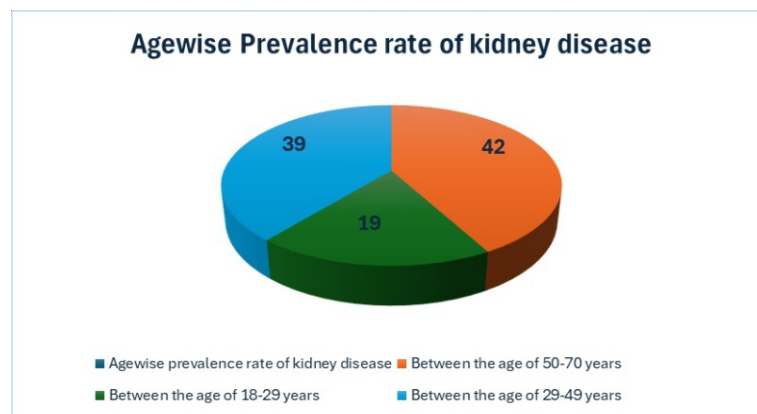
Package for the Social Sciences (SPSS), enabling the identification of patterns, frequencies, and the overall magnitude of the issues under study.

Simultaneously, qualitative data from informal conversations, key informant interviews, and field observations were analyzed using open coding.

Research Findings

3.1 Age-wise prevalence rate of kidney disease

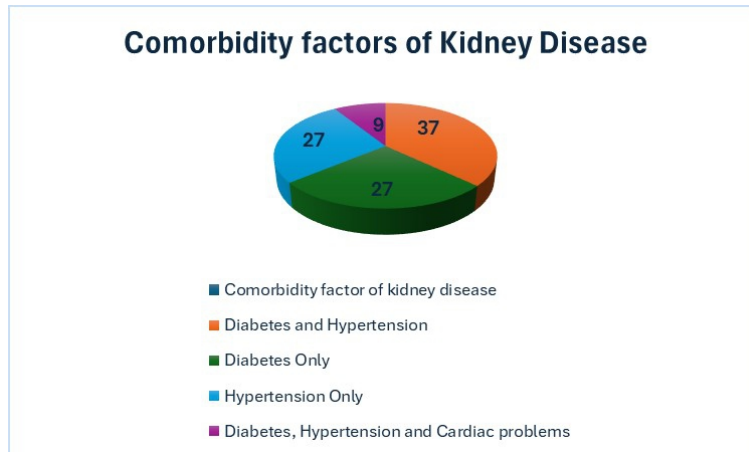
Figure 1: Age-wise prevalence rate of kidney disease



The above-mentioned table indicates the incidence and prevalence of kidney disease among different age groups. The data findings reveal that majority of the patients were elderly. The prevalence rate of kidney disease was 42 % in those aged 50 years to 70 years. Those above 50 years of age showed high prevalence of kidney disease whereas the geriatric population could be considered as a high-risk group. The eGFR (estimated glomerular filtration rate) values have implications for diagnosis of CKD in elderly population (Nitta, Okada, Yana and Takahashi , 2014)

3.2 Comorbidity factor

Figure 2: Comorbidity factor for kidney disease

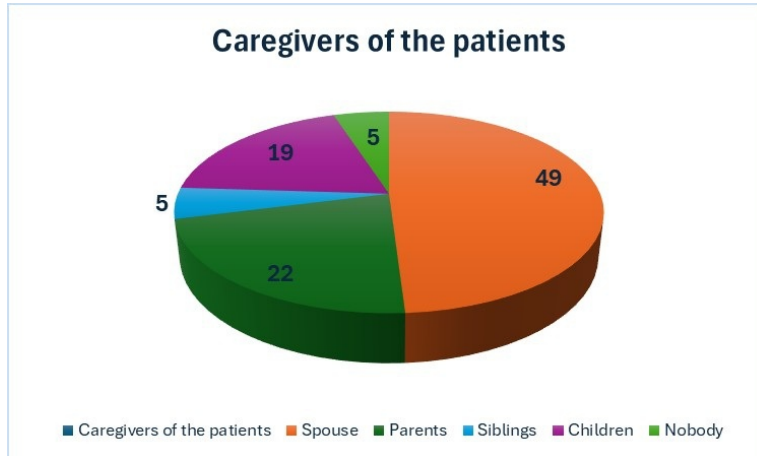


Feinstein was the first to use the term 'comorbidity'. He described it as 'an associated illness arising from other disease' and defined it as any distinct additional entity that has existed or may occur during the clinical course of a patient who has the index disease under study' (Akker, Buntinx and Knottnerus, 1996). The data findings majorly revealed that Hypertension and Diabetes are the contributing factors which lead to failure and damage of kidneys. Nearly 37 % of the kidney disease patients were suffering from Diabetes and Hypertension, 27 % of the kidney disease patients were suffering from Hypertension, 27 % of the kidney disease patients were suffering from Diabetes, 9 % of the kidney disease patients were suffering from Diabetes, Hypertension and Cardiac problems.

The patients with medical history of Diabetes and Hypertension should receive appropriate intervention and care.

3.3 Caregivers of the Chronic Kidney disease patients

Figure 3: Caregivers of the Chronic kidney disease patients



Non-professional healthcare providers such as family, friends are the backbone and support of patients experiencing Chronic kidney disease (Tong, Sainsbury and Craig, 2008).

It is significant to note that the above figure 3 mentions about the caregivers of the Chronic kidney disease patients. The data findings reveal that majority of the caregivers are the spouses followed by parents, children, siblings. Nearly 42 % of the caregivers were the spouses, followed by 19 % being parents, 16 % of the caregivers were the children, and 4 % caregivers were the siblings. However, 19 % dialysis patients had nobody to take care of them.

3.4 Challenges faced by Caregivers

Figure 4: Challenges faced by Caregivers



Caregivers face significant burden and distress which affect their (QOL) quality of life (Vavlianou et al 2023). According to the study conducted by (Alshammari et al, 2021) measuring the Caregivers Burden Scale (CBS), it was found that the individuals belonging to lower socio-economic populations (unemployed or on low income) may experience higher CB (Caregivers burden).

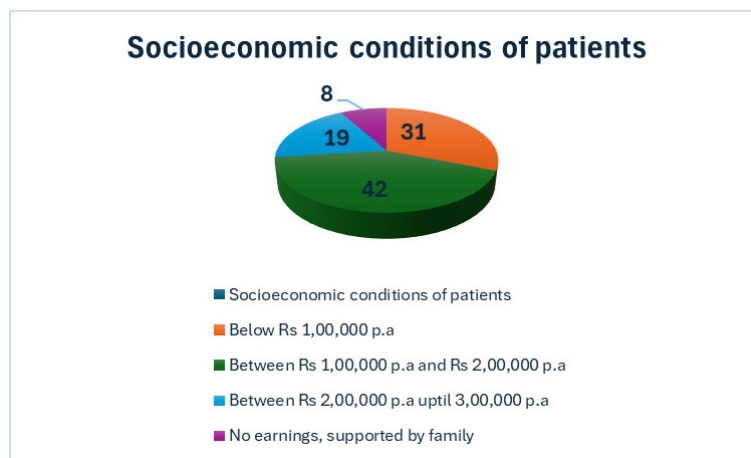
It is significant to note that the above figure 3 mentions about the challenges faced by the caregivers. The data findings reveal that majority of the caregivers face the challenges of managing work and taking care of the patient. Nearly 31 % of the caregivers faced challenges in managing work and taking care of the patient, followed by 27 % of the caregivers being unemployed since they had to accompany the patient, 23 % of them had non-supportive family members, 11 % of the caregivers were themselves suffering from chronic illness and taking care of the dialysis patients, 8 % of the caregivers were supportive towards patients.

Reflecting through the findings, it can be elucidated that health condition of the patients has an impending effect on the caregiver's life. Caregiving role requires support, resilience, patience,

tolerance, strength and continuous availability for the patient. Hence, Caregivers find it difficult to engage in other roles and activities other than caregiving.

3.5 Socioeconomic background of the patient

Figure 5: Socioeconomic conditions of patients



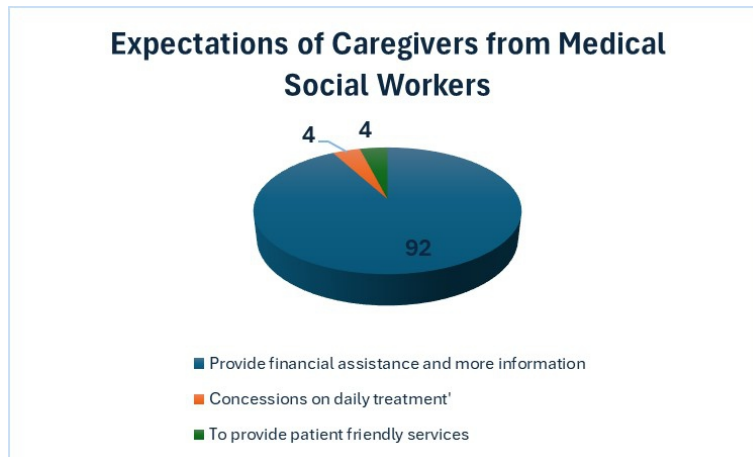
The individuals belonging to lower socioeconomic status (SES) are likely to suffer from unrecognised and untreated CKD as well as end-stage renal disease in both low-income and middle-income countries and developed countries (Zeng et al 2018)

In figure 5, the socio-economic conditions of the patients is discussed. Reflecting on the figure, it can be analysed that majority of the patients belonged to above poverty line. Nearly 42 % of the patients had per annum income between Rs 1, 00,000 to Rs 2, 00,000. Followed by 31 % belonging to below Rs 1, 00,000 p.a. 19 % had annual income between 2, 00,000 to Rs 3, 00,000 and 8 % and no earnings and were supported by family members.

Reflecting through the figure 3 and figure 4, it can be elucidated that most of caregivers were unemployed, majority of the patients belonged to low socio-economic conditions. The medical treatment process incurs heavy expenditure on the patients and their family members.

Expectations of Caregivers from Medical Social Workers

Figure 6: Expectations of Caregivers from Medical Social Workers



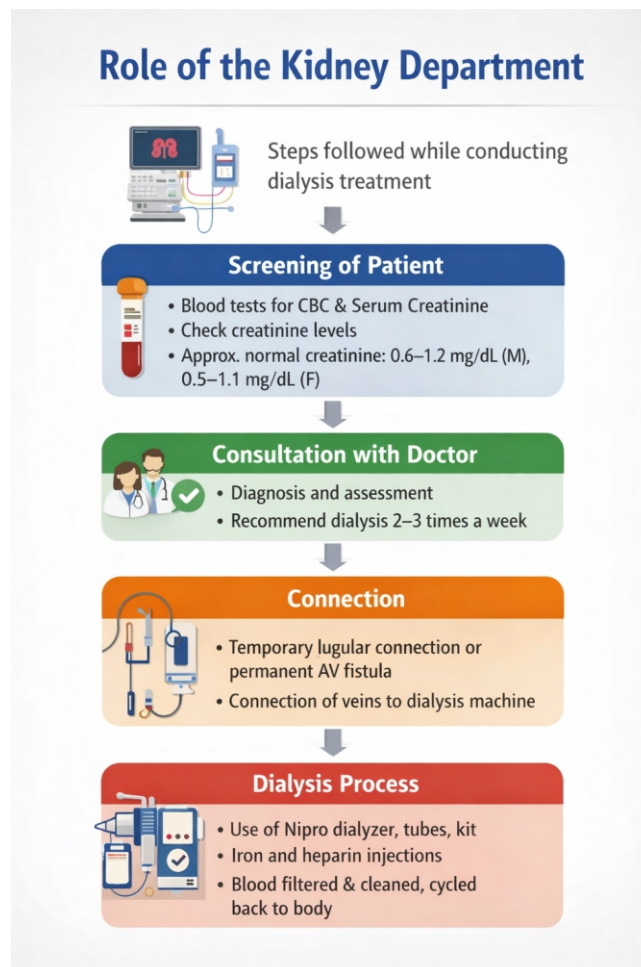
Medical social workers being part of this interdisciplinary team, facilitate health related services and resources for the patients. Social justice mission is shared between the social work and public health profession (Guite, 2019)

The above figure 5 indicates the expectations of caregivers from medical social workers. The data findings revealed that majority of the caregivers expect financial assistance from the medical social worker.

Health expenditures of households in India are largely out-of-pocket expenditures (OOPs), nearly 60 million households fall in the category of below poverty line due to out-of-pocket expenditures (Kaur et al, 2018). Reflecting through figure 5, it can be noted that the need for financial assistance was expressed largely by the caregivers to overcome the financial crisis caused by heavy medical expenditures.

Kidney Department : Providing dialysis care and treatment for the patients

The management of the patient's treatment process is largely the responsibility of the dialysis technician. Initial patient screening, clinical consultation coordination with the doctor, and dialysis treatment facilitation are all part of their duties. The diverse job of the dialysis technician is depicted in the following figure.

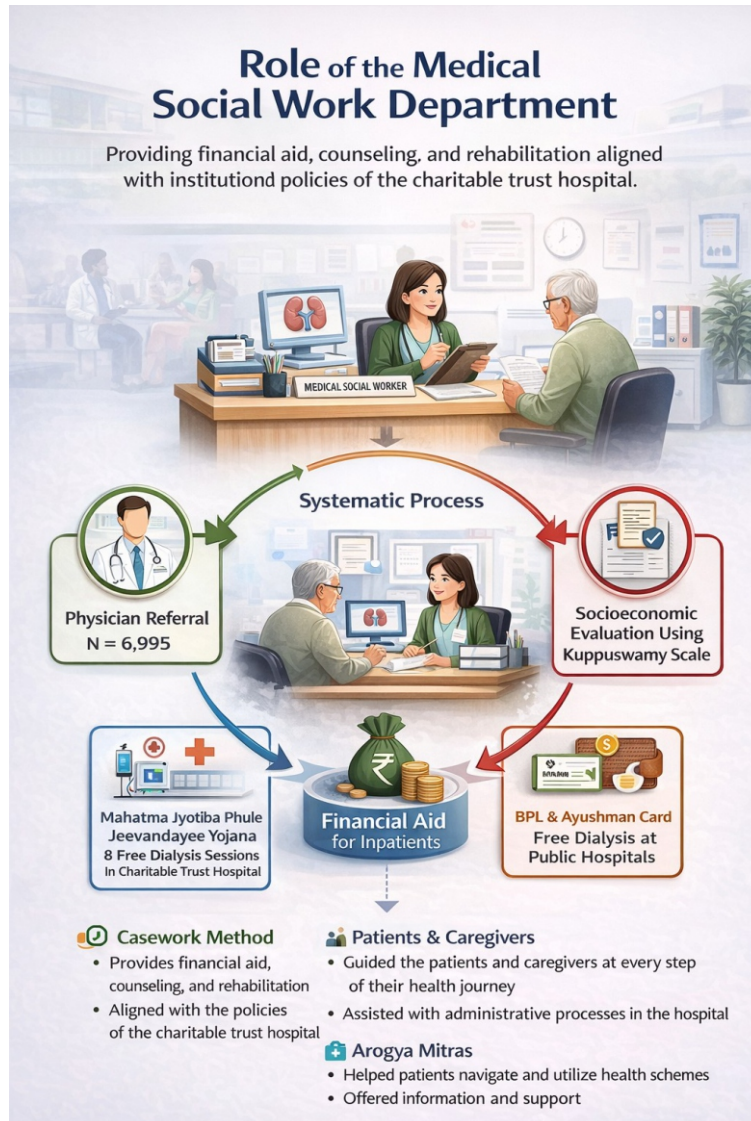


(Source : OpenAI. Role of Kidney Department- image created through primary information gathered during study. 2026. ChatGPT, AI-generated image)

Blood tests are done to screen and diagnose patients, with a focus on serum creatinine levels. High levels of creatinine indicate that the kidneys are not functioning as effectively as they are supposed to. Clinical evaluations and diagnostic reports indicate that patients should undergo dialysis, generally twice or thrice weekly. A permanent arteriovenous (AV) fistula or a temporary jugular catheter are used to create vascular access. Extracorporeal filtration of the patient's blood through a dialysis machine is part of the physically taxing and intense dialysis process.

Role of the Medical Social Work Department

The provision of healthcare facilities is dependent upon the institutional policies aligned with the charitable trust hospital. Using a casework method, the Medical Social Work Department played a crucial role in providing financial aid, counseling, and rehabilitation. After a systematic process that included physician referrals, socioeconomic evaluation using the Kuppuswamy scale, and paperwork, financial aid was mostly given to inpatients. In the studied hospital, under the Mahatma Jyotiba Phule Jeevandayee Yojana, the facility offered eight free dialysis sessions; however, patients were responsible for paying for further dialysis and medications. BPL (Below Poverty Line) and Ayushman card users can receive free dialysis through the Pradhan Mantri National Dialysis Program, but only at public hospitals. The estimated dialysis costs of each patient ranged between ₹17,000 and ₹18,000 per month.



(Source : OpenAI. Role of Medical Social Work Department-
image created through primary information gathered during
study. 2026. ChatGPT, AI-generated image)

The patients and their caregivers primarily rely on the support of the allied health departments. Medical social workers, Arogya

mitras help patients navigate their health journey in the hospital setup. Patients and their relatives spend considerable time waiting for financial support. The administrative process is tedious; it consumes the caregiver and the patient. In such instances, social workers must optimize their administrative processes by creating patient-centered, empathetic processes.

CONCLUSION, SUGGESTIONS AND RECOMMENDATIONS

The action-oriented research and socio-ecological model provided insights to the medical social work intern/ research scholar about the severity of Acute and Chronic Kidney Disease and the need for planning proper interventions for the kidney disease patients. It helped the social worker to study in detail the epidemiology of the disease, health services and schemes provided at Charitable Trust Hospitals. Section 44 A of Charitable Trust Hospitals highlights various provisions entitled to patients. The Mahatma Jyotiba Phule Jan Arogya Yojana (MJPJAY) offers eligible kidney patients up to eight free dialysis sessions. A restricted number of free dialysis sessions under the Mahatma Jyotiba Phule Jan Arogya Yojana (MJPJAY) were included in earlier programmatic descriptions. Recent data, however, suggests that the program currently offers package-based coverage for maintenance hemodialysis, allowing approximately 12 sessions per month (or as clinically recommended), with expenses paid on a per-session basis (Government of Maharashtra, n.d.)

Individuals who are not eligible for this program have to either pay for each dialysis session on their own or are directed by medical social workers to non-profits for financial support. The growing number of individuals on dialysis treatment waiting lists indicates the substantial burden of kidney disease. Dialysis is usually given twice or thrice a week, depending on the severity of the patient's medical condition. It was observed that there were patients coming from a low socio-economic background. The disease brought interdependency on the patient and their caregivers where

the cycle of poverty resulted in the caregivers sacrificing their priorities, livelihood opportunities for providing primary care to the patient.

The following steps can be taken to reduce the disease burden and make services more patient-friendly.

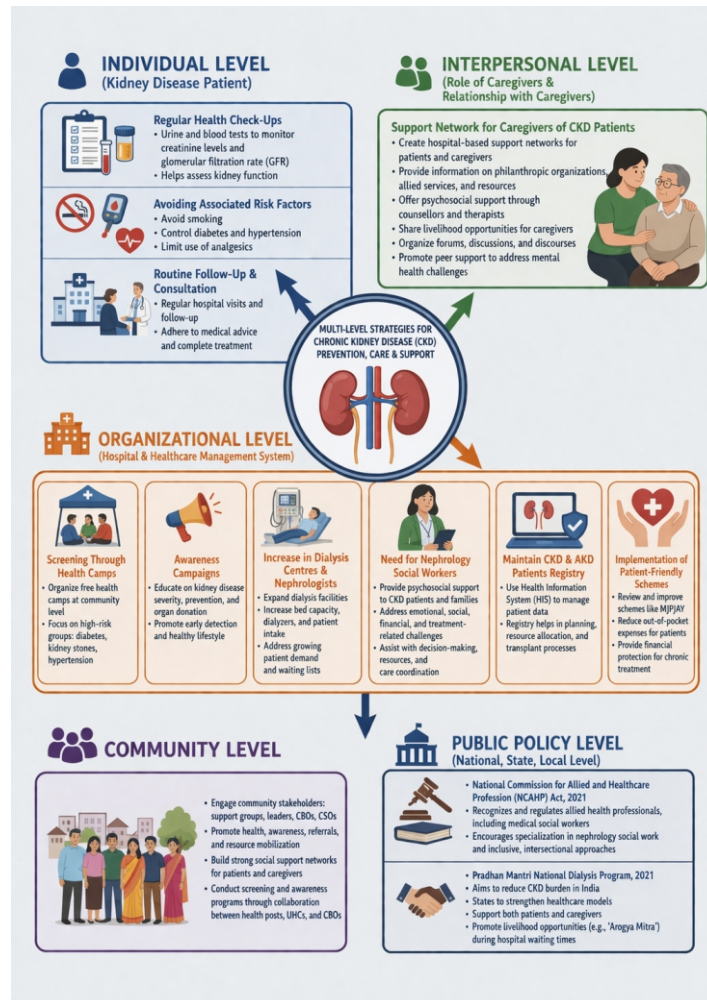
Application of Action Research model in networking and Interlinking with organizations

The research scholar (medical social work intern) by using research findings, drafted a proposal for networking and interlinking organizations working on Kidney care in Mumbai.

These steps were followed to create a strong network and database of thirteen organizations:

- Preparing a list of organizations working towards philanthropy and financial assistance, health related financial assistance.
- Calling the organizations and requesting an appointment.
- Discussing and presenting research-based findings for network building and resource mobilisation.
- Interested organizations collaborating and sharing their details to receive applications of CKD (dialysis patients) from the hospital.
- Sending the dialysis patients to respective organizations to gain financial assistance and support.

The figure below illustrates the multi-level strategies for chronic kidney disease (CKD) prevention, care and support



(Source : OpenAI. Multi-level strategies for managing chronic kidney disease (CKD) prevention, care and support. Image adapted from primary data of the study applying socioecological model . 2026. ChatGPT, AI-generated image)

A. Individual level (Kidney Disease Patient)

- 1. Regular health check-ups** should be done by an individual to check the health status. The urine test and blood test help to identify the creatinine level and the

glomerular filtration rate of kidney and thereby indicate the normal functioning status of the kidney.

2. **Avoid associated risk factors:** Avoiding smoking, keeping diabetes and hypertension under control, less consumption of analgesics.
3. **Routine follow-up, consultation with the doctor and completing the course:** It is important for patients to visit the hospital for routine follow-up and to seek consultation from doctors.

B. Interpersonal level (Role of caregivers, relationship with the caregivers)

1. Creation of Support network for Caregivers of CKD patients

A support network should be created across all hospitals for the caregivers of those patients suffering from chronic diseases. The support network can act as a support system for the patients and their caregivers. This network should focus upon providing information related to philanthropic organizations and allied networks, providing psychosocial support through counsellors and therapists, providing information related to livelihood opportunities for caregivers of the patients. This network can conduct forums, discussions and discourses whereby the caregivers engage with larger audiences. The mental health challenges of the caregivers can be addressed through this network by peer sharing and interaction.

C. Organizational level (Hospital and Healthcare management system)

- i. **Screening through health camps:** Free health camps in community should be organized on a large scale.
- ii. **Focussing on high-risk cases** such as diabetes, kidney stones and hypertension.
- iii. **Awareness campaign:** Organising awareness campaigns about severity of kidney disease, promoting preventive measures and the importance of organ donation for kidney transplant.

iv. Need for increase in dialysis centres and nephrologists:

The disease burden of kidney disease failure is high and the rate is alarming. There is an increase in patient waiting list due to lack of facilities. Either there should be an increase in the dialysis centres or an increase in the bed capacity, dialyzer and dialysis patient intake in the hospital setups.

v. Need of nephrology social workers:

In western countries the nephrology social workers engage and work specifically with the CKD patients. As explained by the 'Council of Nephrology Social Workers', (Teri Browne, 2011- 2013), nephrology social work services support and maximize the psychosocial functioning and adjustment of chronic kidney disease patients and their families.

These services are provided to improve social and emotional stresses resulting from the interacting physical, social, and psychological concomitants of chronic kidney disease which include shortened life expectancy, altered lifestyle with changes in social, financial, vocational, and sexual functioning, conflict resolution, the demands of a rigorous, time-consuming complex treatment, problems related to treatment options and setting transfers, resource needs, including finances, living arrangements, transportation and decision making with regard to advance directives.

vi. Maintaining CKD and AKD patients' registry

Through the Health Information System (HIS) hospitals should manage the data of CKD patients. CKD and AKD registry would be helpful for understanding the magnitude of kidney disease, planning and management of health resources and formulating the process of kidney transplants in the hospital.

vii. Implementation of patient friendly schemes

The MJPJAY scheme provides 8 dialysis free but the patient again has to pay Rs 1250 for the dialysis which some patients found expensive. A patient friendly scheme should be implemented which assures minimum burden of expenditure on the patient. Kidney failure is chronic and amounts to heavy expenditure for the treatment of the patient which often causes family crisis.

D. Community Level

Different community stakeholders such as the community support groups and networks, community leaders, community-based organizations (CBOS), various civil society organizations (CSOs) can play an important role in promoting health, creating awareness, providing referrals, resource mobilisation, forming strong social networks and support for the CKD patients and their caregivers. The local government health post and urban health centres (UHCs) in collaboration with CBOs can conduct various screening and awareness programs on kidney disease in the community.

E. Public Policy (National, State, Local level)

In India, the recent 'National Commission for Allied and Healthcare profession (NCAHP) Act, 2021 to regulate the standards of education and services by allied and healthcare professions including professional social workers working in health and mental health sector came into force on May 25th, 2021. This Act provides opportunities for legal recognition of Professional or Psychiatric social workers in health settings. (Sahu, 2021). There is a gradual shift in traditional/generic practices of social work to specialized practice. It is challenging to formulate a specialized course on nephrology social work. However, there can be amendments made in the existing hospital social work practice. While working with the chronically ill patients, such as CKD patients, the medical social workers should bring an inclusive approach through an intersectionality lens.

The Pradhan Mantri National Dialysis Program, 2021 is a thoughtful step towards reducing Chronic Kidney Disease cases in the country. However, the State needs to review the existing health care models, frame schemes which support not only the patients but their caregivers too. Research study findings revealed that majority of the caregivers face livelihood challenges. The state can promote schemes which provide alternative livelihood opportunities for the caregivers and chronically ill patients. Most of the 'waiting time' in hospital can be used to provide them work in hospital settings such as that of 'Arogya Mitra' in hospitals.

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**UNDERSTANDING DISABILITY AT THE
GRASSROOTS: A NEEDS ASSESSMENT IN RURAL
GUJARAT**

Prof. (Dr.) Lidwin Dias¹, Dr. Kalyani Talvelkar²

Abstract

Disability is a human rights and development issue shaped by social and environmental barriers that restrict equal participation. Persons with disabilities (PwDs) often experience inequalities in education, healthcare, employment, and social inclusion, particularly in rural areas where poverty and exclusion reinforce disadvantage. Limited disability-related data in Koth and Vataman villages of Dholka Taluka poses challenges for evidence-based planning and service delivery. To address this gap, a survey was conducted, with grants from Rashtriya Uchchatar Shiksha Abhiyan (RUSA), among 300 persons with disabilities across 13 villages to assess their health, educational, livelihood, and psychosocial support needs. Findings revealed that most respondents were male, belonged to OBC communities, and lived in joint families. Mobility-related disabilities were the most prevalent, while many participants reported delayed diagnosis or were unaware of the cause of their impairment. Access to healthcare, treatment, rehabilitation services, and assistive devices remained limited due to financial constraints and lack of awareness. The study recommends strengthening inclusive healthcare, education, livelihood opportunities, accessibility, and disability awareness initiatives to promote empowerment and social inclusion.

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Key Words: Rural disability, Challenges of Persons with Disabilities, Livelihood and Healthcare Access, Educational Barriers, Rehabilitation Services

Introduction

“We need to make every single thing accessible to every single person with disability.”

Stevie Wonder (Musician & Activist)

Persons with Disabilities and Human Rights:

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) conceptualizes disability as arising from the interaction between long-term impairments and environmental or attitudinal barriers that restrict full and effective participation in society on an equal basis with others (United Nations, 2006).

Over one billion people are estimated to experience disability. This corresponds to about 15% of the world's population, with up to 190 million (3.8%) people aged 15 years and older having significant difficulties in functioning, often requiring health care services. The number of people experiencing disability is increasing due to a rise in chronic health conditions and population aging (WHO, 2011).

A report named 'Disability Inclusion and Accountability Framework' by the World Bank in April 2022 stated that persons with disabilities are more likely to experience adverse socioeconomic outcomes such as less education, poorer health outcomes, lower levels of employment, and higher poverty rates. Poverty may increase the risk of disability through malnutrition, inadequate access to education and health care, unsafe working conditions, a polluted environment, and lack of access to safe water and sanitation. Disability may also increase the risk of poverty, through lack of employment and education opportunities, lower wages, and increased cost of living with a disability.

Disability is a human rights issue, as people with disability are subject to multiple violations of their rights, including acts of violence, abuse, prejudice and disrespect because of their disability, which intersects with other forms of discrimination

based on age and gender, among other factors. People with disability also face barriers, stigmatization and discrimination when accessing health and health-related services and strategies. Disability is a development priority because of its higher prevalence in lower-income countries and because disability and poverty reinforce and perpetuate one another (WHO 2011).

December 3rd is a significant day for disabled persons since the day has been marked as 'International Day of Persons with Disabilities' by the United Nations since 1992'. The sole motive behind the annual observation of this day is to promote the rights and well-being of persons with disabilities in society; and to increase awareness of the situation of persons with disabilities in every aspect of political, social, economic and cultural life.

As per the report no. 583 of National Sample Survey (NSS): Persons with Disabilities in India NSS 76th round (July – December 2018), the prevalence of disability (percentage of persons with disability in the population) was 2.2% with 2.3% in rural and 2.0% in urban areas. Prevalence of disability was higher among males than females. Among males, the prevalence of disability was 2.4% while it was 1.9% among females. Incidence of disability in the population was 86 per 1,00,000 persons. Nearly half the population of persons with disabilities of 7 years and above (47.8%) were illiterate. Percentage of persons with disabilities of age 3 to 35 years, who were ever enrolled in ordinary school, was only sixty three percent. Less than one fourth population of people with disability in the country (22%) were recipient of any kind of government aid and more than 70% people with disability did not have a disability certificate.

The statistics related to people with disability in Gujarat, reflected similar statistics. Only 23% people with disability had education up to secondary school or above. Only 30% had a disability certificate and nearly 40% of persons with disability in the state of Gujarat were illiterate. Sixteen percent of the total number of people with disability in Gujarat received any kind of government aid (National Statistical Office, 2019).

Challenges faced by Persons with Disabilities in Rural India:

Research studies (Brahmbhatt, 2024; Patel, 2025; Prabhat Education Foundation 2025) have shown that people with disabilities in rural India experience realities that include the following challenges –

- **Poverty and Financial Constraints**
Many families of persons with disabilities lack the financial resources to afford assistive devices, therapies, home modifications, rechargeable batteries, and other supportive equipment necessary for independent living.
- **Unreliable Basic Infrastructure**
Rural areas often experience irregular electricity supply, prolonged power outages, and poor internet connectivity, which limit access to modern assistive technologies and digital resources for persons with disabilities.
- **Health and Nutrition Deprivation**
Poverty and dependence on traditional cooking methods such as firewood-based cooking increase risk and negatively affect the nutrition and health of persons with disabilities. Most household appliances and cooking tools are designed for able-bodied standing users and fail to consider the needs of elderly persons and persons with disabilities, especially those with visual and orthopaedic impairments. Inaccessible environments and unsafe household conditions increase the risk of accidents, burns, falls, physical strain, and worsening of existing disabilities.
- **Barriers to Education**
Children with disabilities in rural areas frequently face delayed school enrolment, school exclusion, lack of inclusive education practices, and absence of appropriate learning support such as sign language interpreters. Rural regions provide limited vocational training programmes, skill-building opportunities, or higher education options for persons with disabilities.

- **Economic Exploitation and Lack of Financial Independence**

Even when persons with disabilities earn an income, especially women, their finances are often controlled or monitored by family members, limiting genuine economic independence.

- **Gender-based Discrimination and Restrictions**

Girls and women with disabilities often experience greater social stigma, overprotection, restricted mobility, and limited opportunities for personal growth and independence.

- **Social Exclusion and Isolation**

Persons with disabilities in rural areas often experience exclusion from social participation, decision-making, and community life.

In many rural communities, disability is viewed through cultural and religious beliefs that encourage dependence and caregiving rather than empowerment, skill development, and autonomy. These studies show that disability is not only a medical condition but is also shaped by societal attitudes, cultural perceptions, discrimination, and lack of inclusive systems, which collectively create barriers for persons with disabilities.

Poor people are more at risk of acquiring a disability because of lack of access to good nutrition, health care, sanitation, as well as safe living and working conditions. Once this occurs, people face barriers to education, employment, and public services which are essential for them to escape poverty. There are structural, physical, social and attitudinal barriers to their attainment of basic human rights. A participatory approach will be needed to determine realities at the micro level and prioritize intervention needs in particular areas like Koth and Vataman.

Koth and Vataman, Dholka Taluka, Gujarat

Dholka taluka covers an area of 1,019.41 square kilometres (393.60 sq mi) comprising 69 villages. A larger part of Dholka is known as Bhal area. Bhal means a dry area where only the babool trees grow. Earlier, people used to cultivate Chana (Gram) and Bhalia wheat, which grow without water after the monsoon. The people did not dare to cultivate any crop like Paddy or Cotton because there were either floods or drought. Now in the monsoon, people grow Paddy as the Narmada Canal water is available if the Monsoon is good.

Dholka, located in the Ahmedabad district of Gujarat, holds profound historical significance, largely due to its 11th-century links with the Solanki dynasty and the revered queen, Maharani Minal Devi (also known as Mayanalla Devi), mother of the famous Jayasimha Siddharaja.

As of 2026, the estimated population of Dholka city (municipality) is approximately 110,000–115,000, based on projections from the 2011 Census which recorded the city population at 80,945 (Census, 2011).

According to census 2011 the total population in Koth village is 10439 and number of households are 2173. Female Population is 47.8%. Village literacy rate is 63.6% and the Female Literacy rate is 25.8%. Total population in Vataman village is 6830 and number of households are 1336. Female Population is 48.2%. Village literacy rate is 64.5% and the Female Literacy rate is 25.5%.

There is a significant lack of reliable and comprehensive data regarding the prevalence and demographic profile of persons with disabilities in Dholka Taluka, Gujarat. The absence of systematically documented statistics poses challenges for evidence-based planning, policy formulation, and the effective delivery of welfare and rehabilitation services. A survey was conducted to address this gap, with the grants from Rashtriya Uchchar Shiksha Abhiyan (RUSA), in Koth and Vataman in 2023-24 to assess the status and needs of persons with disabilities.

Objectives of the Study

The specific objectives of this study were focused on PwDs in Koth and Vataman:

- a. To understand their health needs
- b. To explore their educational needs
- c. To ascertain their livelihood needs
- d. To assess the formal support system (including government initiatives) that is available and accessible to them.

The scope of this study was to get a better understanding of the needs of the persons with disability in the areas of health, education, livelihood as well as the extent of formal and psychosocial support available and accessible to them in Koth and Vataman. The information was intended to enable organizations to prioritize programmatic goals and help identify the intervention needs of this group in Koth and Vataman.

Research Methodology: Planning, Data Collection & Analysis of Field Data

The need assessment survey was a quantitative descriptive study. A combination of purposive and quota sampling was used. NGOs working in this area assisted in identification of the sample. Data was gathered from 300 persons with disabilities in Koth and Vataman clusters in Dholka taluka, Gujarat.

A comprehensive semi-structured interview schedule was designed and administered to study subjects covering information on all major life domains (education, health and livelihood) to identify the main issues and challenges faced by PwDs in Koth and Vataman as well as gauge the support system available to them.

The survey was intended for residents of Koth and Vataman who had disabilities or who were caregivers or guardians of children with disabilities. Participation in the survey was voluntary, data was collected only after obtaining their informed consent.

The data was gathered from 300 respondents across 13 villages in Koth and Vataman clusters in Dholka taluka of Ahmedabad District, Gujarat. The sample was identified with the help of Nirmala Seva Society (NSS), an NGO that has different interventional programmes operational in these areas.

The tools for data collection were first designed in English and then translated into Gujarati, being the regional language. Data collection tool had questions on the following major domains:

- health needs
- educational status
- livelihood needs
- access to formal support system

A one-day rigorous training was conducted for the field investigators at the Dholka center of the Nirmala Seva Society, focusing on administering the tool and ways to handle sensitive questions in the field. One supervisor and two field investigators from each block attended the training. Pilot testing was done to ensure that the interview schedule had validity as well as was constructed in a language that was participatory and inclusive.

The collected quantitative data was then cleaned and entered using excel and Statistical Package of Social Sciences (SPSS) software. The research study followed the ethical guidelines laid down for social work research. Measures were taken to ensure informed consent of the respondents and maintain confidentiality of the data. Given the sensitivity of the issue, efforts were made to ensure that the respondents did not come to any emotional, social, financial or physical harm due to their participation in the research study. Investigators who had experience of working with people with disability were preferred for data collection so that they would have contextual knowledge about the area and community as well as knowledge related to disabilities.

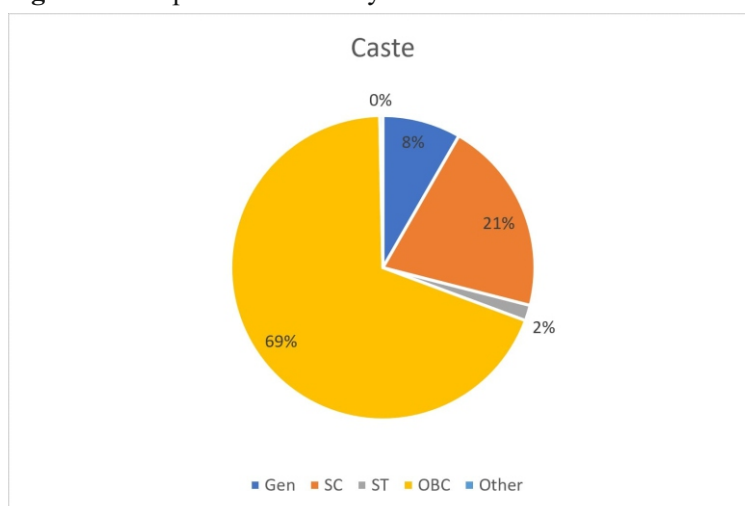
Results and Discussion – Insights into Lived Realities of Persons with Disabilities in Koth & Vataman, Dholka Taluka, Gujarat

Sex and age composition of the sample:

Majority of the research participants were males (60.66%). There were 39.33% female respondents in the study. In terms of age composition of the sample 19% (n = 58) of the research participants were below 18 years of age. Forty two percent (n = 126) of the research participants were in the stage of early adulthood (19 years to 40 years), 35% (n = 104) were in middle adulthood (40 to 64 years) and 4% (n = 12) were in late adulthood stage (65+ years)

Caste composition of the sample:

Figure 1: Sample distribution by Caste



More than two-third of the respondents surveyed belonged to Other Backward Caste (69%) whereas one-fifth of them belonged to Scheduled Castes (21%) followed by General category (8%), Scheduled Tribes (2%). One research participant belonged to the minority group.

Family structure and marital status of the research participants:

Majority of the PwDs in the survey lived in joint families (88%)

followed by nuclear (11.33%) and extended families (0.66%). Nearly two-third families had two to six members (64.33%) whereas one-third of families had more than six members in the family (32%). Some respondents said that they did not have family support:

- Eleven persons with disabilities were reported to be staying alone with no support from their family members.
- Few of them mentioned that they sometimes struggle to feed themselves due to lack of financial resources and persons to assist them.

On inquiring about number of PwDs in the family, two-third of the members had one PwD in the family (74.66%) whereas over one-fifth of the families (22.66%) had two PwDs in the family. Eight families had three and more PwDs in their family.

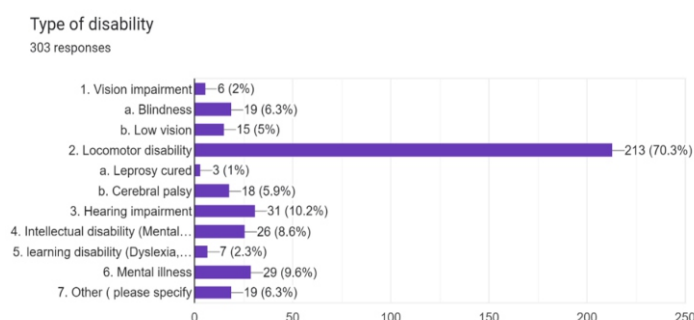
Studies have shown that there is a multidimensional impact (economic, social, emotional, relational and health) on caregivers in the family when there is a member with disability in the family (Lara & Pinos, 2017; Friedman, 2019). When there is more than one family member with disability, the impact would be greater. This finding points to the need for further research in this area.

On inquiring about the marital status of the research participants, it was reported that among those above 18 years of age, 41% (n=102) of the research participants were unmarried, 51% (n=127) were married, 3.6% (n=9) were widowed, 0.8% (n=2) were separated and 3.6% (n=9) were divorced.

The respondents were asked if they think disability creates barriers for getting married. Majority of them replied affirmatively (60.66%) and twelve respondents (4%) replied that sometimes disability was the reason their marriage proposal was rejected.

Disability Related Information:

Figure 2: Types of disability among the respondents



Since the disabilities linked to mobility are of the highest prevalence identified under the study, it reveals the urgent need of physical rehabilitation services along with the provision of assistive devices. This result also highlighted the need to ensure accessible services and an inclusive approach from the service providers. The mobility difficulties experienced by persons with disabilities (PwDs) can become a barrier to access essential services.

It was noted that as many as two-third of the respondents did not know the cause of their impairment (73.33%). In most of these cases, it was prevalent since birth.

Some of the known causes reported were:

- medical negligence (8.3%),
- accident (7.3%),
- Polio (4%),
- paralytic attack (3.33%),
- health issues during pregnancy and childbirth (1.6%) and
- any other (2%).

In case of medical negligence, most of the cases elaborated that they got disability after receiving injections for fever from medical personnel. As the respondents did not have clarity about the cause of their disability or about possible causes of different types of disability, this perception of theirs might not be correct.

Moreover, 27.99% of the PwDs in the study also reported that the

disability remained undetected for some time as is reflected in the table below:

Reasons for late detection were reported to be –

- there was no health facility for detection (38.10%),
- parents were not aware of the disabilities or their symptoms (21.43%),
- the parents or one of the parents felt that there was something wrong/different with the child but other family members did not allow the child to be diagnosed for disability (15.48%),
- inability of the medical professionals to detect the disability. There were nine cases where the medical professional was not able to detect the disability
- Economic reason was reported in four cases.

Eight respondents did not answer this question.

Health Needs and Healthcare Access of the Persons with Disability:

As many as one-third of the respondents did not have access to any treatment (35.33%). Although two-third (66.98%) of PwDs in the study were reported as having accessed medical or therapeutic treatment after detection of their disabilities; only 10 percent of the PwDs in the study are receiving some kind of treatment currently. Lack of awareness about the significance of treatment coupled with financial constraints were the major reasons why the PwDs in the study did not have access to any kind of treatment. (Refer Annexure)

People with disability interviewed in the study had no access to the assistive aids/ appliances as could be seen in the following findings:

- Only one-fifth of the PwDs in the study have been able to access assistive aids/appliances (20.33%).
- A significant majority have never had access to any assistive aids (76.33%).
- Majority of those who reported having used any aids (n=71) had procured these devices through either government organisations (n=28) or NGOs (n=19).

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- Seventeen PwDs mentioned procuring them with the help of family members or self. Seven respondents did not answer this question.

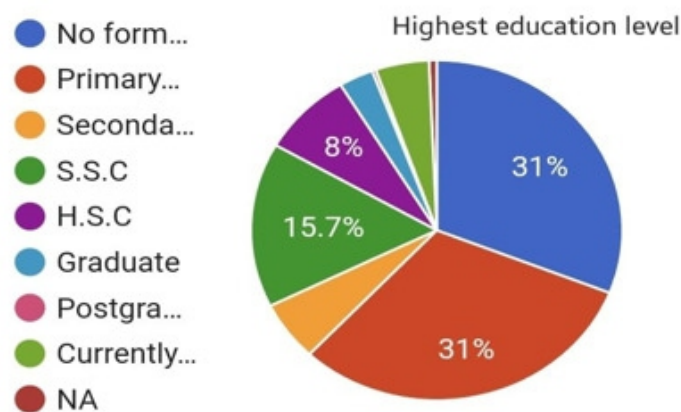
This highlighted a stark gap in accessibility of assistive aids and a need of further access to specialised health care. Close to two-third of the PwDs in the study opined that it is challenging for people with disabilities in Dholka to access adequate health care facilities. Majority of the PwDs in Dholka find it expensive to take treatment. Moreover, cost of travel coupled with cost of assistive aids becomes financially taxing for them.

There were major areas of concern in relation to health needs, such as access to information about treatment and financial assistance, access to medicine especially for chronic illnesses and access to assistive visual and hearing devices.

Educational status, occupation and livelihood needs of the research participants:

The figure given below gives the percentage of respondents with their education level.

Figure 3: Educational Status of the Research Participants



The data indicates that access to education is a great challenge for

PwDs in Dholka. Around one-third of the persons with disability studied under the survey had no access to formal schooling and had never been to school (31%) while another 31 % had to dropout from school after primary education. Only 15.66% could continue their education up to S.S.C and a meagre eight percent were able to complete H.S.C. Only nine respondents were able to study up to graduation level and only one respondent was a post-graduate.

The data revealed that a majority of them had dropped out of education; while a very miniscule number continued with higher education. There was no provision of special schools in the vicinity as stated by majority of the respondents. While interacting with the Staff from the NGOs working in the locality, it was revealed that although school buildings have ramps and wide doors, the washrooms are not disable-friendly and this constrains people with disabilities to access such buildings.

The Disability Act 2016 has made provision of facilitating Special employment exchanges for persons with disabilities. The respondents were asked about Special employment exchanges in their taluka. Two-third of the majority denied having any such provision (77.33%) while 19.66 percent were not aware about this. The study attempted to understand the type of occupation and daily income of the respondents and their families since it is a significant criterion in determining access to healthcare, education and other basic facilities.

The table 1 below describes the type of occupation for the population aged 18 years and above.

Table 1: Occupation of the respondents

Occupational status	Number of research participants
1. Unemployed because of illness/disability	94
2. Begging	1
3. Paid work on family farm/ business	7
4. Daily wage earner	23
5. Own farm	4
6. Self employed (specify)	37
7. Salaried employment (specify)	21
8. Home maker	53
9. Student	4
10. Retired	5
11. No response	51
N	300

Employment and livelihood related problems of the people with disability reflected in the data are:

- More than one-third of the respondents were reported to be unemployed because of illness/disability. Around one-fifth of the respondents were home makers (21.68%).
- Only over one-third of PwDs in the study had access to some kind of employment – self-employed (14.45%), daily wage earner (9.23%), salaried employment (8.43%), own farm (1.6%), paid work on family farm/business (1.2%). Five respondents were retired from work, four were studying.
- One respondent was involved in begging to sustain his living.
- The ones who are engaged in some kind of employment also have meagre income levels. Forty-three percent of them (N=92, n=40) had incomes less than Rs 5000 per month while remaining half of them (47.8%, n=44) had monthly income levels between Rs 5000-10000.
- Only four percent of PwDs (n=4) had monthly income more than Rs 10000.

On inquiring about family income levels eight percent families did not have any income(n=8). Over one-fourth families had monthly income less than Rs. 5000. Half of the families had monthly income in the range of Rs.5000-10000. Only 12 percent families had monthly income in the range of Rs. 10000-20000. Four families were reported earning between Rs. 20000-30000.

The economic struggles of PwDs are reflected as follows:

- The data shows that 46.66 percent of the families were Below Poverty Line; 45.33 percent of families were Above Poverty Line category.
- Seven percent families had Antyodaya ration card.
- Two families reported having no ration card.

Only eleven percent of the PwDs in the study had received some kind of vocational training. Occupation is a significant source of economic independence and may contribute to general well-being of PwDs and their families. The survey results indicate that owing to limited occupation opportunities for PwDs; majority of them have to be dependent on their families for livelihood.

Access to Formal Support:

The study attempted to understand formal support systems available to PwDs in Dholka in the form of accessing governmental schemes and receiving financial assistance entitled to them.

The situation about obtaining a disability certificate was as follows:

- Two-third of the PwDs in the study had access to getting government certificate of disability which is fundamental to accessing any of the basic services (65.33%).
- However, forty-one PwDs reported that they had to face many difficulties while receiving the disability certificate such as
 - lack of cooperation from government officials and medical practitioners.
 - They also found it challenging to reach the offices as they had to travel to reach Ahmedabad.

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- As many as one third of the PwDs in the study do not have the government certificate of disability (34.67%).
 - On inquiring about reasons for not having the disability certificate the following reasons were given:
 - one third of them mentioned that they do not know about it (36.53%),
 - another one third of them mentioned that they were not aware about the procedure for getting it.
 - According to some (4.8%) camps were held at distant places difficult for them to access;
 - Close to four percent were not aware when the camps were held.
 - One of the respondents mentioned that it was difficult to get a disability certificate as he did not have an Aadhar card.

Lack of access to information and subsequently lack of awareness amongst PwDs in the study was a major concern highlighted in the survey data.

Majority of the PwDs in the study were not aware of any Government scheme for financial assistance to the disabled (81%). Only less than one-fourth of them were availing benefits from any of the government schemes for the disabled (23%).

Recommendations

The data visibly highlighted the plight of PwDs in Koth and Vataman. The results suggested a generalised lack of access to basic services like healthcare, education, livelihood and institutional support. It is crucial to create an enabling environment for PwDs to access these social services. The need for awareness generation about the development potential of PwDs is still crucial among the PwDs themselves and the general public.

The lack of access to healthcare services for persons with disability signifies the likelihood of increased secondary health risks for this population.

There are huge gaps in terms of access to education and access to

livelihood opportunities. As compared to their able-bodied peers; unemployment among PwDs is usually high. Owing to discrimination and fewer opportunities PwDs are further pushed into the vicious cycle of poverty and lack of access to basic services. NP 2006 mandates an inclusive society for all and recognizes the fact that a majority of persons with disabilities can lead a better quality of life if they have equal opportunities and effective access to rehabilitation measures.

In terms of educational needs, there is a need to provide disability awareness training for faculty, staff, and administrators in educational institutes. Efforts also need to be made to facilitate course materials in accessible formats.

With regard to occupational needs, research findings highlight a need to plan a comprehensive livelihood strengthening programme for PwDs. This needs to be designed with the full participation of PwDs. In order to rightly address their most urgent needs, livelihood interventions should be established in terms of providing financial support for self-help groups, vocational training and placement opportunities for PwDs

Some other suggestions are listed below:

- Subsidise and increase access to healthcare for PwDs
- Ensure that any services available to PwDs are clearly explained in ways appropriate to them
- Design accessibility in educational buildings, public health centres and government offices.
- There is need to encourage PwDs to form and join associations in order to have a unified, collective strong voice.
- Provide Counselling at the individual, group and family level
- Organize community level disability awareness and sensitization programmes to build an inclusive society. The challenges faced by persons with disability including barriers to marriage have their roots in the negative attitude of people towards persons with disability.
- There is scope of further research in the areas such as

functional assessment of PwDs, impact of having more than one person with disability in the family and communication barriers between people with disabilities and healthcare providers

The findings as well as the recommendations were disseminated to NGOs who plan to use this information to plan their strategies to address these needs and improve the health and quality of life of people with disabilities in Koth and Vataman, Dholka, Gujarat.

Conclusion:

A Disability Rights Perspective emphasizes that a person with disability is entitled to all human rights – civic and political, economic, social and cultural, right to peace, clean environment and fair trade. PwDs need to be treated equally as well as to be given equal opportunities in all domains of life including health, education and employment.

Persons with disabilities encounter structural, physical, social, and attitudinal barriers that impede the realization of their fundamental human rights. A participatory approach is therefore essential to understand realities at the grassroots level and to identify and prioritize context-specific intervention needs in areas such as Koth and Vataman.

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NOTES TO CONTRIBUTORS

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- Authors should ensure that ALL in-text citations have a corresponding reference entry and that each reference entry is cited in the text. Articles with citations but without reference list or vice-versa will NOT be accepted.
 - Key statements in the article may be supported by the author with a logical explanation, the author's opinion, illustration, or in-text citation/paraphrasing of another author's work.
 - Non-citation of others' written work amounts to plagiarism and, thereby, fraud. If plagiarism is identified, the article will not be accepted for publication.
 - Only the last name of the author and the year of publication must be cited in the text.
 - Notes, when necessary should be numbered continuously and should be printed as end notes. Use of footnotes should be avoided.
 - References of both printed and electronic sources should be included at the end of the article in APA format.

References should be listed in *alphabetical order* as follows:

Barai-Jaitly, T. (2002). The health status of children in India: An overview. Seen but not heard: India's marginalised, neglected and vulnerable children, 43-63 New Delhi: VHA

Dhagamwar, V. (2006) Child Rights to Elementary Education: National and International Provisions in Ravi Kumar (ED), The Crisis of Elementary Education in India (pp. 57–91). New Delhi: Sage

Suvarna, Y., Balakrishnan, G. & Talvelkar, K. (2007). The Search of Identity: Placing Universal Birth Registration (UBR) Within the Framework of Child Rights in India in 'Perspectives in Social Work', XXII: 3, 21-37

Singh, S. (2004). Metros perform badly in primary education. Times of India, Mumbai 25.03.2004.

Bikker, A. and Thompson AGH. (2006). Predicting and Comparing Patient Satisfaction in Four Different Modes of Health Care Across a Nation in *Social Science and Medicine*, 63(6), 1671-1683.

Sen, A. (2003). Closing the Gap – Access, Inclusion and Achievement. *The-south-asian.com*, November 2003 Retrieved 5th Jan 2009 from [http://www.thecommonwealth.org/shared_spfiles/uploadedfiles / {F75B1FAA-F88C-43E7-A4B2-B75FEAF6CEF3}_Comm%20Sec20REPORT%2004_V8.pdf](http://www.thecommonwealth.org/shared_spfiles/uploadedfiles/{F75B1FAA-F88C-43E7-A4B2-B75FEAF6CEF3}_Comm%20Sec20REPORT%2004_V8.pdf)

Tables and Figures

- Tables, figures, graphs and diagrams (illustrations) should not be embedded in the text. Place tables and figures after the References section and indicate preferred placement point in the body of the manuscript such as "<Insert Table 1 here>".
- A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included.
- Figures and diagrams should be completely labelled, taking into account necessary size reduction and should be supplied in .gif, .jpg, or .png format with resolution 300 dpi or higher.
- Ensure any colors used in figures will be distinct when converted to black and white for print version.
- The word percent should replace the symbol '%' when it is used in the text, but the symbol '%' can be used in parentheses.

Review System

The review of the manuscript will be blind and impartial. Manuscripts are reviewed by the Editorial Board and peer-reviewers. Accepted manuscripts may be revised for clarity, organization and length. The article will be sent to authors via e-mail for correction and should be returned **within seven days** of receipt. Corrections and editing as suggested by the Editorial Board and peer-reviewers should be undertaken by the author and is not the responsibility of the publisher. The decision of the Editorial Board will be final and binding.

Publication of articles

The accepted articles are scheduled for publication in the chronological order in which they are received. The publication lag of an accepted article is generally one year. Each author gets a complimentary copy of the journal issue in which his/her article is printed.

Communication

Communication with reference to articles should be addressed to:

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GUIDELINES FOR BOOK REVIEWERS

Pre-requisites for a Book Review

The book under review should have been published in the **last two years** and should have direct relevance to the field of social work.

Expectations of a Book Review

The book review can include the following aspects.

- Title of the book (underlined/italicized), edition, name(s) of the author(s)/editor(s), year of publication and name of publisher (separated by a colon), ISBN number, Format (hardcover/soft cover), number of pages and price of the book.
- Objective/theme of the book
- Contents/organization of the book
- Intended audience for the book
- Perceived response of the audience/user (would you recommend it to the user)
- Approach of the book (topical/analytical/chronological /descriptive/ biographical)
- Concise summary of contents
- A critique of the content of the book (language and presentation)
- Remarks on the strengths and limitations of the book, originality, implications for practice, contribution to knowledge, contemporary relevance, applicability to Indian conditions in case of a foreign book, adherence to ethical practices in referencing information)
- Conclusion

A book review could also include:

- A catchy quip/anecdote that succinctly delivers the reviewer's perspective/viewpoint/argument
- Relevant information of the author, where he/she stands in the genre/field of enquiry
- A note (where appropriate) on how well the text is supported by tables/ diagrams illustration
- Quote with a specific page reference. Excessive quotations to be avoided.

Points to note when the book is an edited version comprising chapters from many authors:

- Summary of each chapter or section (in keeping with the abovementioned guidelines)
- Way in which the central theme is dealt with in each chapter or section
- Name of the author and related information

Editing Procedure

The Editorial Board reserves the right to modify the Book Review for length, clarity and content. The reviewer's concurrence to this is assumed, unless specified otherwise by the reviewer.

Typescript for a Book Review

The book review should be typed in 12-point Times New Roman font, double-spaced, with margins of at least one inch on all sides on A4 paper and SHOULD NOT exceed **1500 words**.

Publication of Book Reviews

The Book reviews are scheduled by the Editorial Team of Perspectives as per the quality of the review and contemporary issues. Priority will be given to invited book reviews. Every book reviewer gets a complimentary copy of the journal issue in which their review gets published.

GUIDELINES FOR WRITING DIFFERENT TYPES OF ARTICLES

I. Writing an Article based on a Research Paper/Reports.

This is an article based on an original research project/study, involving information from primary data sources. Such an article contains the following sections:

- Introduction
 - Description of the subject
 - Critical Summary of available information
 - Background of the research
 - Problem identification/ analysis
 - Research questions
 - Rationale for the study
- Methodology
 - Aims of the research
 - Research design
 - Variables
 - Operational definitions
 - Sampling strategy
 - Description of the tools of the data collection
 - Techniques for analysis
 - Limitations of the study, if any
- Discussion:
 - Results of the study: This should include a summarized description of the statistical figures and techniques as well as a concise note on the key findings which could be descriptive or numeric
 - Interpretation of the data in terms of:
 - Validation of the hypothesis
 - Corroboration with cited literature
- Conclusion and recommendations:

This section should include the following

 - Recommendations to improve/remedy the situation
 - Implication for the future research and field practice

II. Writing an Academic Article

This article is based on information from secondary data sources. It generally seeks to raise new issues or examine existing issues from a new perspective. It can also be used for theory building. It should contain the following sections:

- Introduction:
 - Description of the background and importance of the subject under consideration

- Statement of purpose
- Rationale for the article

- Discussion:
 - Critical review of literature
- Gaps in knowledge/services and emerging area addressed:
 - Intervention methods
- Conclusion:
 - Summary of key points
 - Recommendations

III. Writing an Article based on Field Experiences

This article stems from the experiences of the author. It focuses on a specific issue / problem / project / program that is within the purview of the author's professional practice and is descriptive in nature. It provides details of how the author dealt with the specific issue / problem or implemented the program / project under consideration. An overview of such an article is given below.

- Introduction:
 - Description of the subject under consideration
 - Critical review of relevant literature
 - Problem identification/analysis
 - Rationale for intervention
- Discussion:
 - Details of the problem/issue/program/project under consideration
 - Action plan to improve/remedy the situation
 - Details of implementation of the action plan
 - Critical assessment of effectiveness of intervention
 - Learning in relation to existing theory
 - Limitations and suggested modifications
- Conclusion:
 - Summary of key points
 - Suggestions for future work

Submissions that do not conform to the above guidelines will be returned for modifications before entering the review process.



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College of Social Work (Autonomous)

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